



**UNIVERSITY OF  
BIRMINGHAM**

**THE ETHICS OF CARE AND HEALTHCARE DECISION-  
MAKING INVOLVING CHILDREN IN MID-CHILDHOOD.**

**By**

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## **ABSTRACT**

This thesis contends that the traditional legal and ethical approach to healthcare decision-making for children in mid-childhood is insufficient to meet the needs of those children, their families and the professionals that care for them. To address this failing I present a normative framework based on the Ethics of Care to aid in decision-making.

My unique contribution to knowledge is first, to focus on children in mid-childhood (age 8 -14 years old); a neglected group in the jurisprudence, and contend that the current interpretation of *Gillick* competence and best interests fail to fully appreciate the child's capabilities or accommodate the families views. Secondly, I assert that the Ethics of Care is well placed to address the needs of children in this age group, whilst fostering child participation. To this end I develop a novel Ethic of Care framework, based upon the work of Jo Bridgeman. Thirdly, I undertake a systematic review of the case law, spanning a 26-year period, and chart patterns and trends in judicial thinking. Finally, I test the utility of the framework by applying it to three areas on the legal fringes: end of life care, living organ donation and treatment for gender dysphoria.

I dedicate this thesis to my beautiful daughter Olivia Catherine Moreton. The memory of her has been my guiding light over these last 18 years, and the time spent with her has been the inspiration for undertaking this research.

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- Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.
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- In Re Richardson* (1973) 284 So 2d 185 (La App 4<sup>th</sup> Cirt) 338.
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- Little v Little* (1979) 576 SW 2d, Tex.
- McFall v Shimp* 10 Pa D&C 3d 90 (pa 1978).
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*Re A (Male Sterilisation)* [2000] 1 FLR 549.

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*Re W* [1993] (A Minor)(*Medical Treatment*) [1992] 4 All ER 627, [1993] Fam 64.

*Re Wyatt (A Child) (Medical Treatment: Parent's Consent)* [2004] EWHC 2247.

*Re Y (Mental Patient: Bone Marrow Donation)*(1997) Fam 110.

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*Simms v Simms and an NHS Trust* [2002] EWHC 2734 (Fam).

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## **LIST OF LEGISLATION**

Anatomy Act 1984.

Children and Young Persons Act 1935.

Children Act 1989.

Crime and Disorder Act 1998.

European Convention of Human Rights.

Family Law Reform Act 1969.

Human Organ Transplantation Act 1989.

Human Rights Act 1998.

Human Tissue Act 1961.

Human Tissue Act 2004.

Human Tissue (Scotland) Act 2006.

Mental Capacity Act 2005.

United Nations Convention on the Rights of the Child 1989.

UN Convention on the Rights of Persons with Disabilities 2008.

# INTRODUCTION

*“The answer is there is no good answer. So as parents, as doctors, as judges, and as a society, we fumble through and make decisions that allow us to sleep at night – because morals are more important than ethics, and love is more important than law.”*

- Judge DeSalvo in *My Sister's Keeper*.<sup>1</sup>

## 1. Reflections

In 2004 novelist Jodi Picoult published *My Sister's Keeper*.<sup>2</sup> Set in the US, it is the story of 13 year-old Anna and the dilemma that she and her family face when she sues her parents for medical emancipation,<sup>3</sup> purportedly so she can refuse to donate a kidney to her older sister Kate.<sup>4</sup> By way of background, we learn that Anna was conceived as a result of pre-implantation genetic diagnosis - as a “savior sibling”, and throughout her life has donated bone marrow and blood products to Kate, who suffers from acute promyelocytic leukemia. The story resumes at the point where Kate is in end stage renal failure and Anna is expected to act as a kidney donor at potential risk

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<sup>1</sup> Jodi Picoult, *My Sister's Keeper* (Hodder & Soughton 2004) 393.

<sup>2</sup> *ibid* (Hodder & Soughton 2004).

<sup>3</sup> Medical Emancipation of a minor is a US legal concept. Its primary purpose is to release the child from parental involvement in decisions about their healthcare and treatment. The emancipated child may also be deemed to be a ‘mature minor’, which is the equivalent of a ‘Gillick competent’ child under the law of England and Wales. However, a limited guardianship may also be appointed to assist with medical decisions or even make them for the child. There is no equivalent to medical emancipation in England and Wales. See Atherton Godfrey News, ‘Can a Child be Emancipated from its Parents in the UK?’ (31 March 2014) <[www.athertongodfrey.co.uk/news.php?pid=197&p=29&search](http://www.athertongodfrey.co.uk/news.php?pid=197&p=29&search)> Last Accessed 8 August 2016.

<sup>4</sup> In England and Wales, a minor child would need to reach the threshold of competence as laid down in *Gillick v West Norfolk and Wisbeck Area Health Authority* [1986] AC 116 HL, in order to be deemed competent to decide whether or not to act as a living kidney donor. The topic of child living organ donation is dealt with fully in Case Study 2 found in Chapter 5.

to herself, and with only the *prospect* of saving her sister's life. Anna decides that, weary of her identity, and indeed very existence, being defined solely in relation to her sister, she needs to assert her own voice and take control over her own body. The story causes the reader to reflect upon profound questions that go to the core of our essence as relational human beings; the nature of decision-making when it relates to our health, our duties and responsibilities to those we share intimate relationships with, the meaning of being a "good parent" and most crucially, when and how a child can or should be able to make decisions for themselves that relate to their own health.

These questions were all the more poignant for me as in 1998, 6 years prior to reading this novel, I too like Sara - Kate's mother - had been faced with the terrible prospect of a dying daughter.<sup>5</sup> As I reflected upon the profound sense of responsibility that my husband and I felt towards this infant child and her body that we had created, I felt strangely privileged that we were able to take the heart-wrenching decision to switch off her life support. Indeed, contrary to some studies that suggest that it is less emotionally burdensome to parents in these situations for the decision to be taken by the healthcare professional so as to reduce the potential of parental guilt,<sup>6</sup> making that decision ourselves took on a symbolic significance as kind of last service that we could do for our daughter – an ounce of control in an otherwise uncontrollable situation. Furthermore, the key to our "positive" feelings about this most traumatic event was the way that the healthcare professionals involved in her care placed our family relationships at the centre of all they did. In the intervening 18 years I have

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<sup>5</sup> Our eldest daughter Olivia Catherine Moreton was born on 17 November 1997 and died on 7 January 1998 from Septicemia caused by Bacterial Meningitis.

<sup>6</sup> H McHaffie et al, 'Deciding on Treatment Limitation for Neonates: The Parents' Perspective' (2001) 160 European Journal of Pediatrics 339, as discussed in Lacey M Eden & Lynn Clark Callister, 'Parental Involvement in End-of-Life Care and Decision Making in the Newborn Intensive Care Unit: An Integrative Review' (2010) 19 (1) Journal of Perinatal Education 29.

raised five subsequent children and have often pondered my role as a parent in making, mostly routine but nonetheless important, decisions about their health and bodies. As these children have grown and matured through later childhood and adolescence, I began to recognize the tensions between this aspect of my parental responsibility and their clearly emerging abilities to make these decisions for themselves.

This leads me to the topic of this thesis, so neatly encapsulated by the statement made by Judge DeSalvo in *My Sister's Keeper*, quoted above. Confronting dilemmas involving children's health that tax the minds of doctors, parents, judges and society alike, this thesis will raise and seek to answer similar questions. Is the operation of the law, with its precepts of Parental Responsibility,<sup>7</sup> Welfare,<sup>8</sup> and *Gillick* Competence,<sup>9</sup> sufficient alone to deal with children who seek to make these decisions for themselves? Or conversely is DeSalvo J right that these decisions are in fact motivated primarily by the love that we feel as a result of the relationships that we share with others? If this *is* so, how then can, and should, the law accommodate this motivation? Furthermore, are personal morals more important than a set of ethical principles when it comes to healthcare decision-making involving children? Or is there an ethical approach that can cater to the personal, particular and relational, *as well as* successfully underpin decision-making that operates within the certainty of the law? As a Master's student I was introduced to feminist ethics and in particular, the Ethics of Care as a way of determining moral worth in the value that lies in

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<sup>7</sup> Children Act 1989 s3.

<sup>8</sup> Children Act 1989 s1 – note the term 'Best Interests' will be used synonymously with 'Welfare' in this thesis.

<sup>9</sup> *Gillick v West Norfolk and Wisbeck Area Health Authority* [1986] AC 116 HL

interpersonal relationships.<sup>10</sup> Immediately this approach resonated deeply with the understanding that I had gained as a result of my experiences - that valuing relationships was key. Just as the Ethics of Care advocates starting from the particular concrete experience and working upwards, so my very personal experience of confronting the challenge of determining what was “right” in relation to my child’s health, to a large extent shaped my determination to discover if the Ethics of Care might be able to encapsulate all that was needed for good healthcare decision-making for and by children.

## **2. Context**

The debate around decision-making in healthcare has until recent times revolved around the position and opinion of the healthcare professional, often to the detriment of that of the patient and his or her family. In 1957 the courts determined that the legal standard of the duty of care that healthcare professionals owed to patients was determined by the view or practice of a responsible body of those professionals.<sup>11</sup> Writing on this “*Bolam test*”, Margaret Brazier and Jose Miola claim that from its home in medical malpractice and negligence, it ‘infiltrated’<sup>12</sup> other areas of healthcare law and, that out of context, had ‘become the litmus test not just of clinical practice but of medical ethics’.<sup>13</sup> This included, they claim, a ‘covert Bolamisation’ underlying the reasoning in *Gillick* and subsequent case law on child competence and decision-making.<sup>14</sup> However in recent times there has been a shift towards showing greater

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<sup>10</sup> In a course on Criminal Law and Medicine taught by Dr Stephen W Smith at the University of Birmingham, 2011-12.

<sup>11</sup> *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

<sup>12</sup> Margaret Brazier and Jose Miola, ‘Bye Bye Bolam: A Medical Litigation Revolution?’ (2000) 8 Medical Law Review 85.

<sup>13</sup> *ibid* 90.

<sup>14</sup> *ibid* 93-95.

respect for patient autonomy,<sup>15</sup> although as John Coggon and Jose Miola rightly contend, there is much debate about the conception of “autonomy” in this context and the direction that the law and healthcare ethics should take.<sup>16</sup> At the most basic level, the law upholds the necessity for *adults* to provide a voluntary, informed and competent consent to medical treatment as a fundamental tenet of healthcare law and professional practice.<sup>17</sup> Likewise, the common law has been clear for years that a competent adult may refuse any medical care or treatment for any or no reason.<sup>18</sup> However in the last decade and perhaps due to a growing recognition of the importance of Human Rights, the debate around decision-making and capacity to decide has shifted in focus to become more facilitative. This is evidenced by the approach taken in the Mental Capacity Act 2005, which states that all adults are assumed to have capacity unless the contrary is established.<sup>19</sup> The tests to establish lack of capacity set the bar high by requiring both the presence of an impairment or disturbance in the functioning of the mind or brain,<sup>20</sup> *and* evidence of an inability to make a decision stemming from that disturbance.<sup>21</sup> Furthermore it is required that all practicable steps are taken to aid the person to make a decision for himself or herself.<sup>22</sup> However, best interests decision-making is still retained in the MCA for those deemed to lack capacity.<sup>23</sup> Yet, subsequent developments in the commitments in International Treaties such as found in Article 12 of the UN Convention on the Rights

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<sup>15</sup> Graeme Laurie, ‘The Autonomy of Others: Reflections on the Rise and Rise of Patient Choice in Cotemporary Medical Law’ in Shelia McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 131.

<sup>16</sup> John Coggon and Jose Miola, ‘Autonomy, Liberty and Medical Decision-Making’ (2011) 70(3) *Camb Law J* 523.

<sup>17</sup> Department of Health, *Reference Guide to Consent for Examination or Treatment* (2nd edn, 2009) 5; Raanan Gillon, *Philosophical Medical Ethics* (Wiley Medical Publications 1986) 113.

<sup>18</sup> *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 649.

<sup>19</sup> MCA S1 (2).

<sup>20</sup> MCA S2 (1).

<sup>21</sup> MCA S3 (1) (a-d).

<sup>22</sup> MCA S1 (3).

<sup>23</sup> MCA S1 (5).

of Persons with Disabilities 2008,<sup>24</sup> have provoked on-going discussion over whether the best interests paradigm is compatible with the evolution of the law in this area.<sup>25</sup>

Academics such as John Harrington<sup>26</sup> and Jonathan Montgomery, Caroline Jones and Hazel Biggs,<sup>27</sup> have written about the process of law making within medical jurisprudence. Evidence of the issues around decision-making moving forward can be seen for instance, in the recent case of *Montgomery v Lanarkshire Health Board*,<sup>28</sup> which addressed the issue of provision of information as it impacted upon the validity of consent and its potentially controversial shift towards a patient-centred focus and conception of modern patients as ‘consumers’.<sup>29</sup>

However, the debate around children’s healthcare decision-making has perhaps been seen as more challenging, and therefore the same advances have not automatically been extended to children. This may be due to the added complexity of the triadic nature of the decision-making relationship involved - healthcare professionals, child and those with parental responsibility. In addition combine this with the often far-reaching implications of the decision and the tensions between protecting children’s welfare<sup>30</sup> and respecting children’s rights.<sup>31</sup> In law parents are entrusted with

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<sup>24</sup> The Convention was ratified by the UK in July 2009. Article 12 (2) states that ‘States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’. The Committee on the Rights of Persons with Disabilities in General Comment Number 1 has clarified that ‘the best interests principle is not a safeguard which complies with Article 12 in relation to adults’ (para 21).

<sup>25</sup> Rosie Harding, ‘What’s Wrong with Best Interests?’ (27 March 2015) Revaluing Care Research Network <[revaluingcare.net/author/rosie\\_harding/](http://revaluingcare.net/author/rosie_harding/)>; Rosie Harding, ‘Statutory Wills and the Limits of Best Interest Decision-Making’ [2015] 78 (6) Modern Law Review 945.

<sup>26</sup> John Harrington, ‘Time as a Dimension of Medical Law’ (2012) 20(4) Medical Law Review 491.

<sup>27</sup> Jonathan Montgomery, Caroline Jones & Hazel Biggs, ‘Hidden Law Making in the Province of Medical Jurisprudence’ (2014) 77(3) MLR 343.

<sup>28</sup> [2015] UKSC 11.

<sup>29</sup> Jonathan Montgomery & Elsa Montgomery, ‘Montgomery on Informed Consent: An Inexpert Decision?’ (2016) 42 J Med Ethics 89.

<sup>30</sup> As contained in the Children Act 1989 s1.

responsibility for making decisions in relation to their children's health and in circumstances of disagreement, the courts may be called upon to decide by application of the 'best interests' test. Recent cases in the media have highlighted these difficulties. Consider for example, the significant questions about the role and weight of parental views raised by the 2014 case of 5 year-old Ashya King,<sup>32</sup> or the 2008 case of 12 year-old Hannah Jones<sup>33</sup> who chose to refuse a life-saving heart transplant operation, which prompts us to ponder if and when a child is ever competent to make such decisions about their own body and health.

Contemporary bioethical thought has been dominated by Beauchamp and Childress's 'principlism',<sup>34</sup> which has at its heart the four ethical principles of autonomy, non-maleficence, beneficence and justice. Yet, these traditional theories tend to overemphasise 'detached fairness' at the expense of partiality towards those close to us, or the value of 'concrete' real-life situations.<sup>35</sup> This denial of our innate sense that emotions are morally relevant, results in an 'uncaring indifference'.<sup>36</sup> Combine this with the legal basis for decision-making, which has traditionally been founded upon either a paternalistic view of parental duty or the emerging focus upon children's rights,<sup>37</sup> and the result can be an adversarial pitting of parents and children against

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<sup>31</sup> As exemplified by the United Nations Convention on the Rights of the Child 1989, see also Tamara Tolley, 'Hands-Off or Hands-On? Deconstructing the 'Test Case' of *Re G* within a Culture of Children's Rights' (2014) 77(1) MLR 110.

<sup>32</sup> *In the Matter of Ashya King (A Child)* [2014] EWHC 2964 (fam).

<sup>33</sup> Hannah's case is explored in full in Case Study 1 in Chapter 4.

<sup>34</sup> Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (6<sup>th</sup> edn OUP 2008) 25.

<sup>35</sup> Louise Campbell – Brown, 'The ethic of care' [1997] UCL Jurisprudence Review 272.

<sup>36</sup> Beauchamp (n34) 37.

<sup>37</sup> Marie Fox, 'Children' in Jean McHale and Marie Fox, *Health Care Law: Text and Materials* (2<sup>nd</sup> edn Sweet & Maxwell 2007) 407.



each other, against healthcare professionals or even against the courts, instead of ‘sharing responsibility’.<sup>38</sup>

Over the past 30 years critics have sought an alternative ethical approach to assess moral development and the ways that people make decisions - the Ethics of Care is one such approach. As discussed in Chapter 1,<sup>39</sup> it was first advocated by psychologist Carol Gilligan,<sup>40</sup> who sought to include women in her studies on moral development as a way to redress the prevailing androcentric approaches of the time. She claimed that far from women’s morality being under-developed, they instead spoke with a ‘different voice’.<sup>41</sup> This ‘voice’ Gilligan dubbed the ‘ethic of care’, in contrast to the more masculine ‘ethic of justice’. Subsequent work included that of philosopher Nel Noddings’ with her “feminine” theory of care,<sup>42</sup> and Joan Tronto, who took care into the political arena.<sup>43</sup> Yet, since its conception in the 1980s, the Ethics of Care has received its share of criticism as well as praise. For example, Beauchamp and Childress have assessed the Ethics of Care as ‘insufficiently mature’ for inclusion in a philosophical model.<sup>44</sup>

Further it has been criticised as confirming women’s stereotypical care-giving roles,<sup>45</sup> being too focused on need-based relationships<sup>46</sup> or without moral import or intrinsic

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<sup>38</sup> Jo Bridgeman, ‘Caring for Children with Severe Disabilities: Boundaried and Relational Rights’ (2005) 13 *International Journal of Children’s Rights* 99,109.

<sup>39</sup> Chapter 1.

<sup>40</sup> Carol Gilligan, *In a Different Voice: Psychological Theory and Women’s Development* (2<sup>nd</sup> edn 1993 Harvard University Press 1982, 1993).

<sup>41</sup> *ibid* xvi.

<sup>42</sup> Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (University of California Press 1984).

<sup>43</sup> Joan Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (Routledge 1993).

<sup>44</sup> Beauchamp and Childress (n34) 36.

<sup>45</sup> Eve Garrard and Stephen Wilkinson, ‘The Ethics of Care’ Section 4.2 of *Workbook 3: Dilemmas and Decisions at the End of Life* (Open University 2001) 44-46 in Jean McHale and Marie Fox, *Health Care Law: Text and Materials* (2<sup>nd</sup> edn Sweet & Maxwell 2007) 119.

value.<sup>47</sup> However, in recent years there has been a resurgence of interest and redevelopment of care theory. Particularly pertinent to this thesis is the application of care to the law, with legal academics such as Jennifer Nedelsky presenting a model of ‘relational autonomy’,<sup>48</sup> and Jonathan Herring advocating a new way of thinking about legal principles reframed through an Ethic of Care.<sup>49</sup> Whilst building on the old, it is with this new conception of care that this thesis engages.

In terms of the academic literature, the focus has largely been on the position of young children and their parents, or older adolescents, with significant contributions made by Sarah Elliston and Jo Bridgeman. Elliston<sup>50</sup> has undertaken some recent work surveying the applicability of the ‘best interests’ test to children.<sup>51</sup> She purports to overcome some of the criticisms relating to its indeterminate nature<sup>52</sup> by fashioning an alternative model based upon Diekema’s ‘Harm Principle’,<sup>53</sup> combined with the concept of ‘parental reasonableness’.<sup>54</sup> In contrast, Bridgeman in her 2007 monograph *Parental Responsibility, Young Children and Healthcare Law*, as the title suggests focuses only on young children and remains within a best interests paradigm, but suggests Three Guidelines based upon the Ethics of Care to guide to child-decision-making.<sup>55</sup> These guidelines form the basis for the framework developed in this thesis. For children who are potentially competent, Emma Cave has argued that the *Gillick*

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<sup>46</sup> Tim Cockburn, ‘Children and the Feminist Ethic of Care’ (2005) 12 (1) *Childhood* 71, 81 -83.

<sup>47</sup> Peter Allmark, ‘Can there be an ethics of care?’ (1995) 21 *Journal of Medical Ethics* 19-24.

<sup>48</sup> Jennifer Nedelsky, *Laws Relations: A Relational Theory of Self, Autonomy and Law* (OUP 2012).

<sup>49</sup> Jonathan Herring, *Caring and the Law* (Hart 2013).

<sup>50</sup> Sarah Elliston, *The Best Interests of the Child in Healthcare* (Routledge-Cavendish 2007).

<sup>51</sup> The parameters of Elliston’s work are broader than Bridgeman’s in that she doesn’t focus on an age bracket but rather includes any children who are deemed unable to meet the standards for making decisions themselves.

<sup>52</sup> Elliston (n50) 17- 27.

<sup>53</sup> Douglas Diekema, ‘Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention’ (2004) 25 *Theoretical Medicine* 243.

<sup>54</sup> Elliston (n50) 37.

<sup>55</sup> Jo Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (CUP 2007).

test has run its course and suggests that a modified version of the MCA test might be preferable.<sup>56</sup> Yet children in ‘the middle’ remain largely ignored. Despite groundbreaking empirical evidence published in 1996 by Priscilla Alderson and Jonathan Montgomery that children as young as 5 are surprisingly capable of making informed and intelligent decisions about their own health,<sup>57</sup> very little has been written in the intervening 20 years on the topic. It is difficult to ascertain why this is so, but I speculate that the relative dearth of case-law in this area, which in itself is a puzzle, may have served to obscure the important issues which could have been addressed by the academic community. Nonetheless, a small surge of recent cases involving mid-childhood decision-making have perhaps been spurred on by an increased awareness of children’s rights and commitments to facilitate children’s participation and these have revealed a richness of legal and ethical subject matter, which I am eager to explore in this thesis.

### **3. Thesis Questions and Unique Contributions**

This thesis aims to critically examine issues of contemporary legal interest, analysing them from a position grounded in an ethical theory with potential for legal application. Researching this largely neglected age group in the context of healthcare decision-making addresses a gap in the literature. I believe that many of the most interesting legal and ethical questions in this area lie in the “middle”, where a child is not wholly dependent in the way that infants and young children are, but neither are they on the cusp of adulthood in the way that older adolescents are. The overall aim of this research will be to answer the question:

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<sup>56</sup> Emma Cave, ‘Goodbye *Gillick*? Identifying and Resolving Problems with the Concept of Child Competence’ (2013) 34(1) Legal Studies 103.

<sup>57</sup> Priscilla Alderson and Jonathan Montgomery, *Health Care Choices: Making Decisions with Children* (Institute for Public Policy Research 1996).

**Is the ‘Ethics of Care’ an appropriate and workable normative ethical basis for healthcare decision-making relating to children in mid-childhood and if so, how could it be used by policy makers and the courts?**

To answer this the research draws upon knowledge from other disciplines such as medicine, psychology and sociology that are of interest to those who practice as well as research within healthcare law. My overall objective in this thesis is to argue that the current legal and to a lesser extent, medical, mechanisms for healthcare decision-making for and by children in mid-childhood are inadequate. I propose that it would be preferable to utilize an alternative approach using a framework based on an Ethics of Care.

A number of sub-questions will guide this research:

- i) What are the key features of an Ethics of Care and why might it be a fitting ethical approach to underpin healthcare decision-making?
- ii) What are the important ethical and legal factors in mid-childhood healthcare decision-making and how could an Ethics of Care framework be constructed to address these?
- iii) How have the courts addressed mid-childhood healthcare decision-making and is the Ethics of Care compatible with principles such as best interests or *Gillick* Competence?
- iv) How could the courts or healthcare professionals use the Ethics of Care to aid in mid-childhood healthcare decision-making?

The content of these questions as they apply to the structure of this thesis, will be discussed in detail in Section 5 below

My unique or substantial contributions to the field will be first, to focus on children in mid-childhood (age 8 -14 years old).<sup>58</sup> I will contend that the current interpretation of the *Gillick* competence threshold for children and the best interests test used for incompetent children, fail to properly appreciate the capabilities of the child, accommodate the views and needs of the child and their family, or indeed tackle possible tensions between interests of the child and the family. Secondly, I will present a decision-making framework, based upon the Ethics of Care, which I have crafted to address this inadequacy. As noted above, this framework takes the Three Guidelines first presented by Jo Bridgeman in her monograph<sup>59</sup> and develops and expands upon them, especially for use with children in mid-childhood. As explained in Chapter 2,<sup>60</sup> these new Guidelines retain their basis in traditional care thinking but additionally draw upon other theoretical notions closely allied to care theory, such as human capabilities, vulnerability, trust and embodiment that are discussed in Chapter 1.<sup>61</sup> I suggest that this framework will enable judges, parents and healthcare professionals to better address the needs of children in this age group, whilst fostering the greatest measure of participation in the process for the child him or herself. It will

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<sup>58</sup> I will be excluding from this analysis any children who although their chronological age may fall within these parameters, have a disability or disease that renders their “mental age” as something lower, particularly as the concept of what constitutes mental age is controversial. The Ethics of Care framework that is presented in Chapter 2, was designed with children aged 8-14 in mind and the Case Studies in Chapters 4 – 6 in fact all focus on children that are aged between 12 and 14. However, for the purposes of gaining a reasonable sample size for the systematic review in Chapter 3, the search parameters were extended to include 16 year olds, as many of the early children’s healthcare cases in fact involved 16 year olds.

<sup>59</sup> Bridgeman (n55).

<sup>60</sup> Chapter 2.

<sup>61</sup> Chapter 1.

also act as a useful tool to aid decision-makers in their interpretation of the *Gillick* competence threshold and best interests test.

Thirdly, I have made a unique contribution to the literature by undertaking a systematic review of the case law, spanning a 26-year period,<sup>62</sup> identifying all of the relevant mid-childhood healthcare decisions. This review then charts and traces the patterns and trends in judicial thinking, in this area of the law.

Finally, in the latter half of my thesis I take a case study approach to analysing areas of decision-making that are on the legal fringes and which pose interesting moral dilemmas. As none of the three substantive topics discussed has yet generated any case law in England and Wales, I “imagine” the issues that a court may consider. Furthermore, within each of the case studies, I tackle some novel subject areas, for instance in Chapter 4 I consider the possibilities for binding Advance Decisions for children under 18 at the end of life.<sup>63</sup> In Chapter 5 I present a new way of thinking about altruism and duty in living organ donation,<sup>64</sup> and in Chapter 6 I consider a different approach to the balancing of the public and private in relation to personal identity of transgender children.<sup>65</sup> Following this, the substantial contribution in the conclusion is to make practical suggestions and recommendations as to how the Ethics of Care could be incorporated into professional guidance and health practice.

This work is important because in terms of policy, it opens up a dialogue about the validity of incorporating the Ethics of Care into professional guidelines and its use by

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<sup>62</sup> 1990-2016.

<sup>63</sup> Chapter 4.

<sup>64</sup> Chapter 5.

<sup>65</sup> Chapter 6.

the courts. This is beneficial, in that a formal recognition of an Ethics of Care approach may help inform decision-making relating to children in a more comprehensive and personalised way. Further it could assist in more fully determining what is “best” for the particular child, or more readily enable decision-making by the child him or herself. In sum, it may raise awareness within a wider debate of the place and value of caring relationships and how legal rules and frameworks could operate to accommodate these. This is applicable not only within the courtroom but also goes to their impact and function within society, such as in the context of clinical settings and the less formal but perhaps ultimately more influential setting of daily family decision-making.

## **4. Parameters**

### **4.1 Analytical Approaches**

#### **4.1.1 Why Healthcare Law?**

Healthcare Law a relatively new area of the law, whose origins as an academic discipline in the UK can be traced back to the late 1980s and early 1990s. In a recent edited collection on ground-breaking health cases, the editors define medical or healthcare law in terms of ‘(...) the relationship between healthcare professionals (and related institutions) and patients’.<sup>66</sup> In many ways it is “parasitic”, in that it draws upon multiple legal disciplines such as family law, criminal law, tort, and human rights. I have chosen healthcare law as the substantive focus of this thesis because, in contrast to other areas of decision-making that involve children such as education or residence and contact, questions around health pose some of the greatest moral dilemmas and therefore present the richest source of material. Questions on children’s

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<sup>66</sup> Stephen W Smith et al (eds) *Ethical Judgments: Re-Writing Medical Law* (Hart 2017) Glossary 277.

health can run the whole gamut of seriousness, from everyday concerns, such as whether a child should be immunized, to those which have a religious dimension and may impact on a family's standing within their community such as circumcision, through to matters of life and death. Decisions concerning our health involve the most intimate aspects of ourselves, including our bodies, and the choices we make often reflect our core values and can have a profound and lasting impact upon those that we share close relationships with.

#### 4.1.2 - Feminism as an analytical approach

The analytical lens through which I approach both Ethics of Care and much of the law in this thesis is a feminist one. Although, of course there is no single feminism, nor a sole feminist viewpoint on any one issue, it has been claimed that 'emphasis on care as a core value is present in all trends of feminism'.<sup>67</sup> It is clear that the origins of the Ethics of Care lie in the cultural feminism of the second wave of the 1970s and as explained in Chapter 1, its proponents sought an alternative way of viewing moral development as a backlash to the prevailing androcentric, abstract and atomistic norms.<sup>68</sup> As a result they found much in women's practical experiences and ways of thinking and reasoning which they claimed should be celebrated as stemming from feminine attributes and qualities.<sup>69</sup> Some feminists however 'rejected female essentialism, the celebration of a distinctive femaleness together with its maternalistic rhetoric'.<sup>70</sup> However care ethics has kept pace with postmodern thinking and still sits

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<sup>67</sup> Knapp D Van Bogaert & GA Ogunbanjo, 'Feminism and the Ethics of Care' (2009) 51(2) South African Family Practice 116.

<sup>68</sup> Chapter 1.

<sup>69</sup> In particular see Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (University of California Press 1984) and Sara Ruddick, *Maternal Thinking: Towards a Politics of Peace* (Boston, Beacon Press 1989).

<sup>70</sup> Van Bogaert (n67) 116.



well with third wave feminism as it has freed itself from its gender-essentialist roots.<sup>71</sup>

Whilst by no means do all feminist embrace an Ethics of Care, I ally myself in this thesis with those feminists who see value in relational thinking.<sup>72</sup> Also of note, and perhaps not coincidentally, all the key players in my case studies are girls and the vital relationships that are considered in these chapters are those they have as daughters with their mothers or in the case of Chapter 5, that the girl is a mother herself and the relationship she has with her son.

#### 4.1.3 - Ethics and the Law

Although Ward LJ famously said in the conjoined twins case *Re A* that ‘this is a court of law not of morals’,<sup>73</sup> I contend in this thesis that when it comes to decisions about health, that the two cannot, nor indeed should not, be so easily separated. As noted by the editors of *Ethical Judgments*, ‘(...) in relation to healthcare particularly, many of the cases that judges hear have undeniable ethical import’.<sup>74</sup> I agree with Charles Foster and Jose Miola that the stronger the ethical element to a case the greater the argument for the involvement of the law rather than medical professional ethics alone, as whilst medical professionals are best qualified to adjudicate on the *how* of a procedure, in the question of *whether* to do it ‘doctors are no better than non-doctors to make the “correct” decision’.<sup>75</sup> Therefore I begin from the assumption that healthcare decision-making involving children almost always has some ethical dimension to it and that by explicitly taking an ethical approach, even in areas which

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<sup>71</sup> *ibid* 117.

<sup>72</sup> See Annette Baier, ‘What do Women want in a Moral Theory?’ in R Crisp and M Slote (eds) *Virtue Ethics* (OUP 1997); Jennifer Nedelsky, *Laws Relations: A Relational Theory of Self, Autonomy and Law* (OUP 2012).

<sup>73</sup> *Re A (Children) (Conjoined Twins: Medical Treatment)* [2000] 4 All ER 961, [1969].

<sup>74</sup> Smith (n66) 2-3.

<sup>75</sup> Charles Foster and Jose Miola, ‘Whose in Charge? The Relationship between Medical Law, Medical Ethics and Medical Morality’ (2015) 23(4) *Medical Law Review* 505, 511.

appear to be governed by the law, that decision-making is both richer and more accurately reflects the private concerns and interests of the family involved.

## 4.2 Epistemology and Methodology

### 4.2.1 Systematic Review

A Systematic Review is a type of literature (or in this instance, case law) review of all the secondary sources falling within certain research parameters and time frames.<sup>76</sup> It has most often been used in medical science<sup>77</sup> but has some precedent in legal analysis.<sup>78</sup> This was chosen as the methodology for analysing the case law discussed in Chapter 3 as a means of evaluating how judges approach the issue of mid-childhood healthcare decision-making. The search parameters were set to identify any case which had as its sole or main focus an issue involving a child's health or body and which involved a child aged between 8 and 16 years old. The time frame was set as January 1990 to August 2016, a time period of almost 26 years. The commencement date of 1990 married with the introduction of vital pieces of legislation relating to children. These include the Children Act 1989, which came into force in 1991, and the United Nations Convention on the Rights of the Child, which was signed by the UK in April 1990 and ratified in December 1991. Furthermore, the first modern case where the Courts actively considered a child's involvement in a decision about his own medical treatment – *Re E* - was heard in 1990.<sup>79</sup> A huge variety of substantive topics within the case law were identified, including cases

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<sup>76</sup> Pippa Hemingway and Nic Brereton, *What is a Systematic Review? What is...? Series* (2<sup>nd</sup> edn, Hayward Medical Communications 2009).

<sup>77</sup> *ibid*

<sup>78</sup> See for example, Ray Pawson, *Does Megan's Law Work? A Theory-Driven Systematic Review* (ESRC UK Centre for Evidence-Based Policy and Practice, Working Paper, 2002) 8.

<sup>79</sup> *Re E (A Minor) (Wardship: Medical Treatment)* [1992] 2 FCR 219

involving blood transfusion,<sup>80</sup> organ transplantation,<sup>81</sup> treatment for anorexia nervosa,<sup>82</sup> circumcision,<sup>83</sup> immunization<sup>84</sup> and abortion.<sup>85</sup> However, despite this heterogeneity, by identifying certain phrases in the search parameters around the legal principles used in the judgments such as ‘best interests’, ‘welfare’, ‘parental responsibility’ or ‘Gillick Competence’ this methodology enabled me to trace trend and patterns in judicial thinking over a relatively large period of time.

#### 4.2.2 Case Studies and Narrative Analysis

In the second half of the thesis the Ethics of Care framework will be tested out by way of case studies. I have chosen this methodology as it provides for ‘in-depth, multi-faceted explorations of complex issues in their real life settings’,<sup>86</sup> and this is particularly well suited to healthcare scenarios. Key to this approach is the ability to consider a single issue in great depth and to assess it within its ‘naturalistic’ context. To the extent that this “story” or narrative approach mirrors bottom-up, concrete ways of ethical reasoning, it is exactly the starting point advocated by the Ethics of Care.

### **5. Thesis Structure**

In **Chapter 1** I consider sub-question i) *What are the key features of an Ethics of Care and why might it be a fitting ethical approach to underpin healthcare decision-making?* In this chapter the genesis and development of the Ethics of Care are examined. The implications of the Ethics of Care as feminist theory and its

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<sup>80</sup> *Re S (A Minor)(Refusal of Medical Treatment)* [1995] 1 FCR 604.

<sup>81</sup> *Re M (A Child)(Medical Treatment)* [1999] All ER (D) 798.

<sup>82</sup> *Re C (A Minor)(Detention for Medical Treatment)* [1997] 3 FCR 49.

<sup>83</sup> *Re S (Children)(Specific Issue Order: Religion: Circumcision)* [2004] EWHC 1282 (fam).

<sup>84</sup> *F v F* [2013] EWHC 2683 (Fam).

<sup>85</sup> *An NHS Trust v A, B, C and a Local Authority* [2014] EWHC 1445 (fam).

<sup>86</sup> Sarah Crowe et al, ‘The Case Study Approach’ (2011) 11(100) BMC Medical Research Methodology 1.

relationship to other moral theories will be evaluated. Further, its utility and compatibility with the way that parents make medical decisions for their children will be assessed. Previous research will be studied, which suggests children themselves use an Ethics of Care approach to make decisions.<sup>87</sup> I consider the utility of the Ethics of Care as an applied ethical theory to underpin a framework for use in mid-childhood healthcare decision-making. I conclude that care is best conceived of as a moral orientation which encompasses modes of thinking arising from concrete practical experience, prompts questioning rooted in reciprocal caring relationships and compels practical action founded on the concepts of vulnerability, embodiment and trust.

In **Chapter 2**, I tackle sub-question ii) *What are the important ethical and legal factors in mid-childhood healthcare decision-making and how could an Ethics of Care framework be constructed to address these?* I begin by introducing how philosophical and ethical approaches have conceptualized the child. I contend that developmental psychology remains a privileged source of knowledge, combined with the sociological concept of the child as a future ‘becoming’<sup>88</sup> to create a model of childhood as a time of innocence and the child as a subject to be nurtured to adult competence.<sup>89</sup>

I then move on to consider the main paradigms used in contemporary healthcare law in relation to children’s decision-making and assess how particular consideration is given to the unique power that parents have to make decisions on behalf of their children, alongside an evaluation of the development of the concept of child

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<sup>87</sup> Carol Smart, Bren Neale and Amanda Wade, *The Changing Experience of Childhood: Families and Divorce* (Cambridge, Polity Press 2001).

<sup>88</sup> Chris Jenks, *Childhood* (2<sup>nd</sup> edn, Routledge 2005).

<sup>89</sup> Joel Feinberg, *Rights, Justice and the Bounds of Liberty* (Princeton University Press 1980).

competence and the rise in children's rights. I claim that neither the keystone of patient autonomy for the atomistic adult patient nor the best interests test for the dependent child patient, fully address the 'many interesting questions' raised by the position of the child in mid-childhood.<sup>90</sup> In particular, I highlight that the experience of children in mid-childhood, is one of change, with greater focus upon emotional and social worlds than the physical growth of earlier childhood. Accordingly my thesis recognizes that children's relational identity within families, peer groups and social, cultural and religious communities is key to understanding their needs and capabilities.

Towards the end of this chapter I present a framework for decision-making based on the Ethics of Care and developed from guidelines proposed by Jo Bridgeman. The model consists of three guidelines and begins with the presumption that the greatest moral value lies within the child's relationships. Guideline One is 'Attentiveness to the Individual Interconnected Child in her Particular Circumstances', which draws on concepts such as vulnerability, embodiment, the child's voice and the child's expertise produced from their lived experience. Guideline Two is 'Consideration of the Child's Past and Future Caring Relationships', which focuses on the quality of caring relationships, the expertise of caring parents, the needs of family members individually and together, and the future impact on the family of any decision. Guideline Three is 'Evaluation of the Social Context of Care' and this guideline assesses issues of social, cultural and religious importance, as well as considering the potential resource implications of any decision.

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<sup>90</sup> Samantha Brennan, 'Children's Choices or Children's Interests: Which do their Rights Protect?' in David Archard D and Colin Macleod (eds) *The Moral and Political Status of Children* (OUP 2002).

In **Chapter 3**, I consider sub-question iii) *How have the courts addressed mid-childhood healthcare decision-making and is the Ethics of Care compatible with principles such as best interests or Gillick Competence?* Here I apply the care framework to the process of judicial interpretation of ‘best interests’ and whilst I argue that ‘best interests’ remains the pragmatic choice for determining incompetent children’s healthcare choices, I identify five key shortcomings of the test. Likewise I consider the merits of the *Gillick* competence test. These are then assessed in a systematic case review of all mid-childhood healthcare cases over a 26-year period, between 1990 - 2016 and the concept of ‘just caring’ is proposed in response as a way for judges to adopt the moral orientation of care. Subsequently, the application of the framework in the context of judicial decision-making is demonstrated through a case analysis of the recent refusal of immunization case of *F v F*.<sup>91</sup>

There then follows a short transition section, which explains that the second half of the thesis consists of three case studies. It is in these chapters - **Chapters 4-6**, that I consider sub-question iv) *How could the courts or healthcare professionals use the Ethics of Care to aid in mid-childhood healthcare decision-making?* The case studies explore the practical application of the framework in an area of moral and legal significance to mid-childhood. Although all three guidelines of the care framework will be considered in each chapter, there will a primary focus on one guideline in each chapter.

**Chapter 4** contains the first case study, which is on end-of life care and focuses on Guideline One. The chapter consists of a narrative analysis of the case of 12-year old

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<sup>91</sup> [2013] EWHC 2683 (fam).

Hannah Jones who refused to consent to a potentially life saving heart transplant and will argue that the adoption of a care orientation might allow for more creative and particularist decision-making at the end of life.

In **Chapter 5**, I explore the second case study, which tackles the topic of living organ donation and focuses on Guideline Two. Here I draw on a fictional scenario of 14 year-old Ella who wishes to donate her kidney to her 18 month-old son Thomas.<sup>92</sup> The analysis seeks to justify the thorny question of whether it is ever justified for a child to participate in an invasive and permanent procedure that is not medically beneficial to them.

**Chapter 6** contains the final case study, which centres the treatment of transgender children and focuses on Guideline Three. This chapter presents the case of trans-girl Jackie Green and critically analyses a new treatment protocol for transgender children being trialled by the Tavistock Clinic, London to consider the social, cultural, political and resource implications in an area that is medically and relationally contentious.

In my **Concluding Thoughts** I briefly summarise the current position of the law in relation to mid-childhood healthcare decision-making and why I believe that a framework based on the Ethics of Care would help to address some of the shortcomings in the current approach. I draw together the patterns of judicial thinking observed from the systematic case review and then demonstrate how the care framework has been useful in illuminating different ways of thinking via the three case studies. In the concluding chapter I will also acknowledge that whilst this

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<sup>92</sup> A version of this scenario was suggested by Dr Joe Brierley, Paediatric Consultant at Great Ormond Street Hospital, which I have used as the basis for the modified version that I present in Chapter 6.

approach is able to tackle the 'dark side' of care by seeking to honestly analyse relationships rather than romanticising them, care theory may have its limits. Finally I will propose practical means whereby the care framework may be implemented in legal and clinical practice and make suggestions for further research.



## **PART 1 – THEORETICAL AND LEGAL PERSPECTIVES**

### **CHAPTER 1**

#### **EXPLORING THE ETHICS OF CARE**

*‘It has the potential of being based on the truly universal experience of care. Every human being has been cared for as a child or would not be alive’.*

-Virginia Held.<sup>1</sup>

#### **Introduction: Why care about the Ethics of Care?**

The Ethics of Care as a distinct normative approach to moral questions first arose out of the feminist thinking of the 1970’s and early 1980’s. In the subsequent 30 or so years, it has been subject to endless scrutiny, adaption, praise and indeed criticism. Yet, it has remained an enduring and popular approach and one with a significant practical legacy within applied ethics, with ‘care models’ being found in areas as diverse as politics, social policy, law, medicine and business.<sup>2</sup> Many advocates of the Ethics of Care claim that it is rooted in ‘an understanding of the most basic and most

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<sup>1</sup> Virginia Held, *The Ethics of Care: Personal, Political and Global* (OUP, New York 2006) 3.

<sup>2</sup> For example in politics, see Held (n1) and Joan Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (Routledge 1993); in Social Policy, see Marian Barnes, *Care in Everyday life: An Ethic of Care in Practice* (Polity Press 2012); in Law, see Jo Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (CUP 2007); in Medicine, see Lawrence Schneider, Kathy Faber-Langenden and Nancy Jecker, ‘Beyond Futility to an Ethic of Care’ (1994) 96(2) *The American Journal of Medicine* 110; and in Business, see Thomas White, ‘Business Ethics and Carol Gilligan’s “Two Voices” (1992) 2(1) *Business Ethics Quarterly* 51.

comprehensive values'.<sup>3</sup> Although intuitionism has been dismissed as a weak basis for an ethical approach,<sup>4</sup> I argue that as a starting point there *is* power in the intuitive notion<sup>5</sup> that there is 'moral significance in the fundamental elements of relationships and the dependencies in human life'.<sup>6</sup>

I shall use the plural 'Ethics of Care' when describing this approach to encapsulate the idea that there is no singular description or model of what it means to care in the moral sense. Some advocates have claimed that the ethics' legitimacy arises from its ability to reflect women's practical experiences in a way that traditional ethics has been unable to. But Alisa Carse and Hilde Nelson argue that a gender-bias thesis is insufficiently narrow, and that the true source of the ethics' legitimacy is in the need 'to be honest about what is required for human flourishing'.<sup>7</sup> I agree with Ruth Groenhout that the legitimacy of the Ethics of Care rests in an ideal of human flourishing that is based upon a caring, interdependent, embodied and socially connected picture of human nature.<sup>8</sup> This observation perhaps points to the distinguishing feature of all the approaches to care; that adherents eschew traditional abstract, universalist principles and instead focus upon the particularities of concrete relationships, complete with all their vulnerabilities and dependencies, and use this interconnectedness as a guiding source in determining how to think, feel and act morally.

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<sup>3</sup> Held (n1) 3.

<sup>4</sup> Michael R DePaul, 'Intuitions in Moral Inquiry' in David Copp (ed), *The Oxford Handbook of Ethical Theory* (OUP, New York 2006)

<sup>5</sup> Peta Bowden, *Caring: Gender-Sensitive Ethics* (Routledge, London 1997) 1.

<sup>6</sup> Maureen Sander-Staudt, 'Care Ethics' (2011) The Internet Encyclopedia of Philosophy <[www.iep.utm.edu/care-eth/](http://www.iep.utm.edu/care-eth/)> Accessed 12 February 2013.

<sup>7</sup> Alisa L Carse and Hilde Lindemann Nelson, 'Rehabilitating Care' (1996) 6(1) *Kennedy Institute of Ethics Journal* 19, 30.

<sup>8</sup> Ruth Groenhout, *Connected Lives: Human Nature and an Ethic of Care* (Rowman and Littlefield 2004) 24.

Early advocates of the Ethics of Care, such as Sara Ruddick<sup>9</sup> and Nel Noddings,<sup>10</sup> and indeed more recent ones such as Virginia Held<sup>11</sup> and Ruth Groenhout<sup>12</sup> have claimed that this intuitive notion of the importance care, relation and connectedness is evidenced by harkening back to the memory our first relationship; the maternal one. Such advocates claim that the mother-child relationship is the paradigmatic model upon which to construct a theory of care.<sup>13</sup> Whilst many have viewed care as merely a personal morality, care's potential has been vastly extended, with some advocates such as Noddings<sup>14</sup> and Held<sup>15</sup> making the sweeping claim that we should care about care because it is the very foundation upon which all morality rests. Held makes the radical claim that without asserting the prime value of the experience of care, there can be no justice or liberal autonomy to be concerned with, as care is essential for both human survival and continued flourishing.<sup>16</sup>

In this chapter, I too claim that we should care about care and that the Ethics of Care can provide a fitting and useful normative framework to assist us in determining the answers to moral problems. I will begin by exploring the genesis of the Ethics of Care. This will be done in detail because I contend that the themes arising from the work of Carol Gilligan, Sara Ruddick and Nel Noddings, are both foundational and persuasive. Next, I consider the definition of care and assess its theoretical status and ontological nature. Whilst I resist both an overly sentimental picture of care, and making universal claims about its applicability, I agree with Peta Bowden's assertion

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<sup>9</sup> Sara Ruddick, 'Maternal Thinking' (1980) 6(2) *Feminist Studies* 342

<sup>10</sup> Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (University of California Press 1984).

<sup>11</sup> Held (n1).

<sup>12</sup> Ruth Groenhout, 'Care Theory and the Ideal of Neutrality in Public Moral Discourse' (1998) 23(2) *Journal of Medicine and Philosophy* 170.

<sup>13</sup> Ruddick (n9).

<sup>14</sup> Noddings (n10) 7.

<sup>15</sup> Held (n1) 13.

<sup>16</sup> *ibid* 14.

that caring is ‘transforming interpersonal relatedness into something *beyond* ontological necessity or brute survival’.<sup>17</sup> I reason that the Ethics of Care is a stance that best reflects the natural inclination to care which is often, albeit not always, a vital expression of human nature. My view is that care has greater depth when constructed as a moral orientation which encompasses thought, attitude and action and under which an applied ethical theory may be developed which takes as its core, not virtue or right-action but the value of relationships. The criticisms of care shall then be addressed and I hope largely rebutted, in part by outlining how later developments in care thinking have tackled some of these objections. Finally I consider how care and the law may be reconciled by exploring associated concepts such as justice, trust, vulnerability and embodiment. I conclude by advocating the construction of a normative care theory by drawing upon Jo Bridgeman’s notion of ‘relational responsibility’,<sup>18</sup> and contend that it could be used within the family and daily healthcare settings, as it reflects well the deeply interconnected relationship of parent and child. Likewise I propose that ‘just caring’<sup>19</sup> is an entirely fitting approach for the judiciary to take when making medical decisions relating to children.

## **Section 1 - The Genesis of the Ethics of Care: Key Themes**

### **1.1 Gilligan’s ‘Different Voice’.**

It is traditional to attribute the formulation of the distinct relational approach to morality, known as the ‘Ethics of Care’ to psychologist Carol Gilligan.<sup>20</sup> Beginning in the 1970’s Gilligan began to question the prevailing methods of measuring moral

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<sup>17</sup> Bowden (n5) 1 emphasis added.

<sup>18</sup> Bridgeman (n2).

<sup>19</sup> Christine Koggel, ‘Care and Justice: Re-Examined and Revised’ (The Paideia Project Online, 20<sup>th</sup> World Congress of Philosophy, August 1998) <[www.bu.edu/wcp/index.html](http://www.bu.edu/wcp/index.html)> Accessed 21 March 2013.

<sup>20</sup> Carol Gilligan, *In a Different Voice: Psychological Theory and Women’s Development*, (2<sup>nd</sup> ed 1993 Harvard University Press 1993).

development, such as Jean Piaget's two-stage theory of cognitive development<sup>21</sup> and Laurence Kohlberg's pre-conventional, conventional and post-conventional six-stage hierarchical model.<sup>22</sup> Drawing upon Kantian abstract notions of duty, justice and autonomy as the preeminent driving forces of morality, Kohlberg claimed that the aim of moral education should be to encourage development from one stage of his model to the next.

Gilligan was disturbed by the discrepancy between men, who mostly demonstrated at least stage 4 reasoning,<sup>23</sup> and women who appeared to be 'stuck' at stage 3;<sup>24</sup> the 'Interpersonal Accord and Conformity Orientation', marked by conformity to social expectations and maintenance of relationships.<sup>25</sup> Yet, she was well versed in, and seemed to accept the viability of the six stages, and as Gunnar Jorgensen persuasively argues Gilligan never saw herself as a *critic* of Kohlberg's but rather she wished to expand upon his model by presenting a different paradigm 'where she would listen for people's moral language, their voice, in a real-life setting'.<sup>26</sup>

Gilligan claimed that Kohlberg's model was insufficient as a moral theory on two levels. Firstly, she argued that Kohlberg's work was overly androcentric. The core

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<sup>21</sup> Jean Piaget, *The Moral Judgment of the Child* (Free Press, New York 1965).

<sup>22</sup> James Rest, Clark Power and Mary Brabeck, 'Lawrence Kohlberg (1927-1938)' (May 1988) 43(5) *American Psychologist*, 399.

<sup>23</sup> Lawrence Kohlberg, *Essays in Moral Development – Volume 1* (1981) 409-12. Stage 4 reasoning is 'Maintaining the Social Order' and is taken from the point of view of society as a whole. It is distinguished by an emphasis on obeying laws, respecting authority and performing one's duty.

<sup>24</sup> Gilligan (n20) 18.

<sup>25</sup> W C Crain, 'Kohlberg's Stages of Moral Development' in W C Crain *Theories of Moral Development* (Prentice-Hall 1985) 125. 121.

<sup>26</sup> Gunnar Jorgensen, 'Kohlberg and Gilligan: Duet or Duel?' (2006) 35(2) *Journal of Moral Education* 179, 194.

sample for his original study was 84 boys aged between 10-16.<sup>27</sup> She noted that an absence of female subjects created an underlying assumption that male reasoning was the norm and that any deviation from this norm, was thereby viewed as a deficiency.<sup>28</sup> Rosemarie Tong notes that Gilligan ‘hypothesized that the deficiency lay not in women but in Kohlberg’s scale (...) and that if women were measured on a female-sensitive scale, they would prove just as morally developed as men’.<sup>29</sup>

Secondly, she was concerned with the emphasis upon the predominance of a justice orientation as the highest achievement of moral development. It can be argued that Kohlberg’s ‘norm’ with its emphasis on impartiality and equality was constructed under a very white, middle-class, male, ‘Western-centric’ view of morality. Indeed, Joan Tronto has argued that Kohlberg’s model functions to ‘produce, and to justify, a morally adept elite’.<sup>30</sup> Further, Gilligan’s objection related to the justice orientation’s preference for abstraction which she argued did not correlate with concrete real-life experience of moral decision-making.

To tackle these two objections, Gilligan undertook three empirical studies of her own on the subject of moral development and used as her core themes the notions of voice, difference and men and women’s development.<sup>31</sup> To counter the first objection, she sought female subjects in an attempt to identify if the inclusion of women did show moral deficiency, or if they could add anything new to the moral picture. In her 1982

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<sup>27</sup> Crain (n25) 119. This study consisted of an interview where the boys were presented with a moral dilemma such as ‘Heinz and the Druggist’ and asked for their reasoning as to whether the proponent of the scenario had made the right decision.

<sup>28</sup> Gilligan (n20) 14.

<sup>29</sup> Rosemarie Tong, *Feminist Approaches to Bioethics: Theoretical Reflections and Practical Applications* (Westview Press 1997) 39.

<sup>30</sup> Tronto (n2) 63.

<sup>31</sup> Gilligan (n20) xv.

book<sup>32</sup> Gilligan demonstrated that some women did indeed speak with a ‘different voice’, which voice she defines as ‘being human, as having something to say, as the meaning at the core of self, but with the caveat that ‘speaking depends on listening and being heard: it is an intensely relational act’.<sup>33</sup>

Her second objection was answered by listening to what the ‘different voice’ was saying. This ‘voice’ can be constructed in terms of how the individual views the concept of self. In the ethic of justice, Gilligan argued that ‘the individual’ is viewed as just that – separate, autonomous and equal. She claims what marked out the ‘different voice’ was ‘concern about relationship that made women’s voices sound different within a world that was preoccupied with separation and obsessed with creating and maintain boundaries between people (...)’.<sup>34</sup> In listening to the different voice she determined that moral problems arose from conflicting responsibilities rather than competing rights and are resolved using thinking that is contextual and narrative rather than that which is detached and abstract.<sup>35</sup> This alternative ethic she dubbed the ‘Ethics of Care’, which is constructed upon ‘a network of connection, a web of relationships that is sustained by a process of communication’.<sup>36</sup> Within such an ethic, morality lies in helping others, in serving, in ‘meeting one’s obligations and responsibilities to others, if possible without sacrificing oneself’.<sup>37</sup>

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<sup>32</sup> Gilligan (n20).

<sup>33</sup> *ibid* xvi.

<sup>34</sup> *ibid* xiv.

<sup>35</sup> *ibid* 19.

<sup>36</sup> *ibid* 32.

<sup>37</sup> *ibid* 66.

Gilligan's study of women considering abortion,<sup>38</sup> resulted in her proposing an alternative model of moral development, which although in many ways mirrors Kohlberg's in being hierarchal and tripartite, is distinguished by its focus not upon cognitive development but on a 'critical reinterpretation of the moral conflict between selfishness and responsibility'.<sup>39</sup> The abortion study is perhaps her most interesting application of the Ethics of Care, as she examined women's decision-making processes not from the familiar stances of women's autonomy versus fetal rights but from the viewpoint of 'mature' care thinking arising from the notion of the woman taking care of herself. This contrast is best demonstrated by examining the movement through the three stages.

The first stage, which entails an overemphasizing focus on self, was demonstrated in the abortion study by a woman's focus on the autonomous self as survival mechanism when confronted with being alone. The transition into the second stage, is marked by a view of judgments regarding the self as selfish. Instead the self is seen as relational and the good is defined solely as caring for others. In the abortion study this was framed in terms of parental responsibility, an emphasis on social participation and consensual judgments about goodness, which may have given more weight to concerns about the status of the fetus. The third stage can be seen as a 'reconsideration of responsibility and relationships'; a time to resolve conflict between self and others, where mature care sees calls of 'goodness' transformed into 'truth'. Here, blind sacrifice is rejected and care is a self-chosen principle of judgment.<sup>40</sup> In the abortion study, those operating at this level considered if they could

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<sup>38</sup> *ibid* 73

<sup>39</sup> *ibid.*

<sup>40</sup> *ibid* 74.



be responsible to themselves as well as others, a decision achieved by the application of honesty.

I contend that although Gilligan's identification of the feminine moral voice is a valuable product of her work, the most powerful legacy of her thesis lies in her novel focus upon the relationship between the concept of self and others. Gilligan's insight was perhaps the first time that we were alerted to the possibility that a focus upon the dominant (typically male) justice-based approaches, might result in us missing out on an important element of morality - that which 'reflects a cumulative knowledge of human relationships, evolves around a central insight, that self and other are interdependent'.<sup>41</sup>

### 1.2 Sara Ruddick and Maternal Thinking

Virginia Held<sup>42</sup> attributes the genesis of the Ethics of Care to an earlier essay entitled 'Maternal Thinking' by philosopher Sara Ruddick.<sup>43</sup> Writing from the feminist perspective of the late 1970's and early 1980's Ruddick begins with an observation of female traditions and practices, such as the care of children, to assess if they might give rise to a distinctive way of *thinking* as a result of engaging in the practice.<sup>44</sup> She constructs as her central question 'Do women, who now rightfully claim the instruments of public power, have cultures, traditions and inquires which we should insist upon bringing into the public world?'<sup>45</sup> This emphasis on maternal *thought*, was novel for philosophy, which had previously dismissed maternal practice as merely emotional, and this 'bottom-up' approach was in stark contrast to the prevailing

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<sup>41</sup> *ibid*

<sup>42</sup> Held (n1).

<sup>43</sup> Ruddick (n9).

<sup>44</sup> *ibid* 346.

<sup>45</sup> *ibid* 345.

philosophical thought of answering moral questions by the application of generalized, abstract principles. Her goal was to show that it was possible to honour ideals of reason<sup>46</sup> but shaped by notions of responsibility and love rather than by emotional detachment, objectivity and impersonality.<sup>47</sup>

Although Ruddick maintains her focus upon women's experiences, and attributes 'maternal thinking' to a combination of female biology and feminine gender roles, Andrea O'Reilly claims that 'Ruddick, in repositioning the word "mother" from a noun to a verb, de genders motherwork'.<sup>48</sup> In terms of developing a contemporary care theory for use in bioethics and the law, this latter approach is preferable as it allows for broader appeal whilst still acknowledging its roots within the experience of women. Indeed 30 years later, Ruddick writes ' (...) the work or practice of mothering is distinct from the identity of the mother. Mothering may be performed by anyone who commits him- or herself to the demands of maternal practice'.<sup>49</sup> A more egalitarian approach may also be better suited to contemporary practices of parenting, where I will argue that this 'maternal thought' or caring orientation should be and is cultivated by fathers in a similar manner to mothers.

Ruddick identifies three goals of maternal practice, those of preservation, growth, and acceptability of the child in the social world.<sup>50</sup> The first is the demand by the child for preservation and protection, which is met by the work of preservative love and employing characteristics such as humility and cheerfulness as a means of mitigating

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<sup>46</sup> Sara Ruddick, *Maternal Thinking: Towards a Politics of Peace* (Beacon Press, Boston 1989) 61.

<sup>47</sup> Bowden (n5) 25.

<sup>48</sup> Andrea O'Reilly, ' "I envision a future in which maternal thinkers are respected and self-respecting": The Legacy of Sara Ruddick's *Maternal Thinking*' (2009) 37 (3&4) *Women's Studies Quarterly* 295, 297.

<sup>49</sup> Sara Ruddick, 'On *Maternal Thinking*' (2009) 37 (3&4) *Women's Studies Quarterly* 306.

<sup>50</sup> Ruddick (n9) 348.

the uncertainties of a dangerous and unpredictable world.<sup>51</sup> These are characteristics that exemplify women's refusal of 'a sharp division between inner and outer, or self and other',<sup>52</sup> and Ruddick argues are applicable outside of the practice of maternal-care itself.

The second goal is the child's demand for the nurturance and fostering of their growth. In this area, maternal thought requires attention to context, a focus on the particular and a willingness to accept change.<sup>53</sup> At this stage there is also recognition of the tension between dependency and emerging separation, 'a delicate balancing of vulnerability and submission, abandonment and domination'.<sup>54</sup> The third goal is in response to the demands of society that the mother should raise up a child who is acceptable to the values of the society in which they live. Here maternal practice requires a form of 'training' of the child and navigating the conflict between maternal and social values, and the resultant fight against 'inauthenticity' when the mother fails in self-care and cedes to social expectations.<sup>55</sup>

I agree with Peta Bowden that the utility of Ruddick's work is that she 'shows us a realm of human interaction that persuasively challenges conventional conceptions of ethical exchanges, as contracts or utilitarian calculations'.<sup>56</sup> If Ruddick's 'preservative love' is taken as a synonym for 'care', then she may have been the first to identify the Ethics of Care. Indeed, Ann Bradshaw equates care with the concepts such as

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<sup>51</sup> Ruddick (n46) 70.

<sup>52</sup> Ruddick (n9) 352.

<sup>53</sup> Ruddick (n46) 89.

<sup>54</sup> Bowden (n5) 28.

<sup>55</sup> Ruddick (n46) 113.

<sup>56</sup> Bowden (n5) 37.

‘*agape*’, ‘*philia*’, or Christian love.<sup>57</sup> However, Ruddick’s work has been criticized both as ‘essentialising’ - in the sense that ‘mothers as persons in their own right, with their own needs and desires within and apart from their maternal roles, seem to be invisible (...)’ - and as positing a relation isolated from the economic and social conditions which impact it.<sup>58</sup> This notion of harmful self-sacrifice has been an enduring concern of the Ethics of Care but it is important to note that ‘mature care’ as described by Gilligan would reject such an idealised self-sacrificing love. William Puka’s observation that care is a set of interpretive skills and sensibilities, proclivities and habits which are easily observed and verified and more realistic than the concept of *agape*,<sup>59</sup> is probably closer to the vision of care that Ruddick was seeking. Likewise, her values may be viewed not as sentimental but as Sara Hoagland argues, an expression of enabling possibilities or ‘creative choices’<sup>60</sup> between the ‘possibilities that lie between the twin dangers of overweening control and unquestioning submission’.<sup>61</sup>

### 1.3 - Nel Noddings’ Feminine Care Theory

Closely following the publication of Gilligan’s findings, Nel Noddings posits an Ethics of Care model that is explicitly feminine.<sup>62</sup> Her work moved beyond psychological observation to develop a cogent *theory* of care. Margaret Walker observes that Noddings’ model holds that the motivation to be moral is to be found in

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<sup>57</sup> Ann Bradshaw, ‘Yes! There is an Ethics of Care: An Answer for Peter Allmark’ (1996) 22 *Journal of Medical Ethics* 8.

<sup>58</sup> Bowden (n5) 43.

<sup>59</sup> William Puka, *Moral Development* (2005) Internet Encyclopedia of Philosophy <[www.iep.edu/moraldev/](http://www.iep.edu/moraldev/)> Accessed 11 February 2013.

<sup>60</sup> Sara Hoagland, *Lesbian Ethics: Toward New Value*, (Institute of Lesbian Studies, Palo Alto California 1988) 69.

<sup>61</sup> Bowden (n5) 28.

<sup>62</sup> Noddings (n10).

creating and maintaining caring relations,<sup>63</sup> which stems from a conviction that the caring relation is ethically basic - *intrinsically* a human good.<sup>64</sup> This view is persuasive if one takes, as I do, Groenhout's stance<sup>65</sup> that the expression of care is the 'ethical ideal' and the essence of human flourishing. This can be contrasted with Gilligan's approach, which Walker argues is an affirmation of caring for its *extrinsic or instrumental* value as 'a condition for the fullest and most direct pursuit of such goods (...)',<sup>66</sup> as equality, honesty, harmonious relationships or non-violence.<sup>67</sup>

Noddings is quick to clarify that her views regarding the feminine nature of care are not essentialist. They are feminine by virtue of their connection to experiences rooted in 'receptivity, relatedness and responsiveness'.<sup>68</sup> She claims they arise as women enter the domain of moral action 'through a different door'.<sup>69</sup> This difference is marked by a desire to appreciate the particulars of a situation, to value relatedness and to utilise 'ethical feeling', rather than the 'masculine' starting point of abstract moral reasoning'.<sup>70</sup> Her model functions on the basis that the memory of caring and being cared for, is the foundation of ethical response<sup>71</sup> and her approach is similar to Ruddick's in that she uses concrete relationships as a way to view and resolve moral problems, with the maternal relationship acting as the paradigm for care.<sup>72</sup>

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<sup>63</sup> Margaret Urban Walker, 'What does the Different Voice Say? Gilligan's Women and Moral Philosophy' (1989) 23 *The Journal of Value Inquiry* 123, 128-29.

<sup>64</sup> *ibid*

<sup>65</sup> Groenhout (n8) 24.

<sup>66</sup> Margaret Urban Walker, *Moral Contexts* (Rowman and Littlefield 2003) 65.

<sup>67</sup> Walker (n63) 128-29.

<sup>68</sup> Noddings (n10) 2

<sup>69</sup> *ibid* 2.

<sup>70</sup> *ibid*

<sup>71</sup> *ibid* 1

<sup>72</sup> *ibid* 8.

Noddings constructs the caring relationship as a three step process between the ‘one-caring’ and the ‘cared-for’, whereby the mutual responsibilities of each come together in relationship or as they ‘meet one another morally’.<sup>73</sup> The first step is for the ‘one-caring’ to feel ‘engrossment’ in the situation of the ‘cared-for’. This engrossment represents a process of reception where there is a shift away from self and towards receiving ‘the other into myself and I see and feel with the other. I become a duality’.<sup>74</sup> The concept of engrossment, if interpreted as a concerted effort to really understand the other’s viewpoint, free from our own personal desires and biases, can illustrate well the kind of thinking that is necessary for care to be an effective approach. However the appropriateness of this kind of engrossment has been criticised as being unfeasible in professional contexts, unhealthy in intimate ones and generally too demanding upon the ‘one caring’.<sup>75</sup> In response, Noddings might argue that engrossment need not be the all-consuming practice that her critics have portrayed it to be. She has claimed that engrossment does not necessarily need to be intense or pervasive, as this will depend upon the particulars of the situation, but that it is legitimate for engrossment to be an acceptable mental attitude in any relation, whether private or public, as our ‘first and unending obligation is to meet the other morally as one-caring’.<sup>76</sup>

This engrossment then inspires the second step of ‘Motivational Displacement’ which requires the ‘one-caring’ to act in accordance with the needs or interests of the ‘cared-for’. This is a vital step within an applied Ethics of Care, where theory moves into action. This action is not to follow some prescribed rule of conduct but to ‘act with

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<sup>73</sup> *ibid*

<sup>74</sup> *ibid* 30.

<sup>75</sup> Helga Kushe, *Caring: Nurses, Women and Ethics* (Blackwell 1997) 149.

<sup>76</sup> Noddings (n10) 17.

special regard for the particular person in a concrete situation'.<sup>77</sup> Noddings outlines two steps to be used by the third party observer in order to ascertain whether the action is motivated by care. Firstly, the action either brings about a favourable outcome for the cared-for or is likely to do so. Secondly, the one-caring shows a characteristic variability in her actions, guided by a broad and loosely defined ethic rather than acting in a rule-bound fashion.<sup>78</sup>

The final and perhaps most contested step, turns our attention to the 'cared for' who must 'Recognise or Respond' to the caring in order for it to be 'completed'.<sup>79</sup> This element of reciprocity is problematic in that there may be circumstances where the 'cared for' is unable or unwilling to reciprocate. It is surely inconsistent to state that caring thought, felt and performed by the 'one caring' is incomplete for lack of reciprocity and I would disagree with Noddings that it is a *necessary* aspect of care. However, reciprocity may be an important element of care in respect of the self-validation and authentication of care for the 'one-caring'. This may be particularly apt in the context of this thesis where the roles and responsibilities of children within the caring relationship will be considered in relation to decisions about their own healthcare. Here what is important is not only how a child is able to reciprocate the care extended by parents, nurses and the judiciary but also what role he can play in becoming one-caring himself.

Although Noddings is conscious of the need to heed the particulars of each situation and relationship, thereby rejecting more formal, universal, principle-based ethics as

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<sup>77</sup> *ibid* 24.

<sup>78</sup> *ibid* 25.

<sup>79</sup> *ibid* 24.

ambiguous and unstable,<sup>80</sup> she is also attentive to the requirement for a theory of care to establish some fundamental overarching universality in order to escape charges of relativism.<sup>81</sup> She attempts to strike a balance between generalism and particularism by advocating the necessity of a universally accessible ‘caring attitude’ which ‘expresses our earliest memories of being cared for and our growing store of memories of both caring and being cared for (...)’.<sup>82</sup> She argues that by adopting this ‘attitude of care’ a process of ‘concretization rather than abstraction’ will be required as certain feelings, memories and capacities are activated.<sup>83</sup>

However, this position is problematic. Although I acknowledge that there may be value in her claim that the desire for caring relation is an innate aspect of human nature,<sup>84</sup> Noddings appears to be taking a substantial leap to claim that caring memories and experiences are universally accessible. Unless care is to be defined as mere physical subsistence (which neither Noddings or I endorse), then it is clearly the case that for some people their early memories and indeed their later experience, may in fact be not of care but of abuse or neglect. Noddings is unsuccessful in dealing with those who are unable to care, by dismissing them as to be avoided because they are ‘beyond our normal pattern of understanding.’<sup>85</sup> This raises interesting issues about whether those who are pathologically unable to offer or receive natural care, such as psychopaths, are therefore completely outside of the ambit of the Ethics of Care. However, it is important to note that although the absence of memories of early natural care may make the generation of a caring attitude more difficult, I would

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<sup>80</sup> *ibid* 5.

<sup>81</sup> *ibid*

<sup>82</sup> *ibid*

<sup>83</sup> *ibid* 8.

<sup>84</sup> *ibid* 83.

<sup>85</sup> *ibid* 81.



argue that for most people this does not automatically preclude the ability to care throughout life, which Noddings claims ‘lies latent in us, awaiting gradual development (...)’.<sup>86</sup>

The most useful part of Noddings’ model for the purposes of this thesis, particularly in relation to healthcare professionals and judges, is her consideration of how to foster the ability to care in circumstances where it does not arise naturally. Noddings rejects Kant’s proposition that caring done out of duty is morally superior to that done naturally on the grounds that the former requires more of us ethically than the latter. Instead she powerfully presents the two as interconnected, with ‘ethical caring’ arising from the enabling sentiment of the memory of ‘natural caring’.<sup>87</sup> This ‘ethical ideal’ is a picture of ourselves as ‘one-caring’. Noddings claims that everything is dependent upon the nature and strength of this ideal as, in the absence of moral principles, it will act as the sole guide in determining how to meet the other morally.<sup>88</sup> Ethical caring may be connected to virtue, in the sense that it is the development of a certain disposition of the best self and a commitment to the “I must” of caring thought and action.<sup>89</sup> Noddings argues that the one-caring’s response to the “I must” is a reflection on the value of actual caring and the goodness that arises in these situations, but that such obligations are by necessity limited by proximate relation.<sup>90</sup> Once another steps into our circle of relation we are obliged to care, by asking ourselves ‘Am I meeting the other morally’?

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<sup>86</sup> *ibid* 83.

<sup>87</sup> *ibid* 79.

<sup>88</sup> *ibid* 5.

<sup>89</sup> *ibid* 81.

<sup>90</sup> *ibid* 86.

Of course, none of these approaches are without difficulties, many of which will be considered in section 2 below. In some ways these early approaches can be seen as responses to the concerns of second wave feminism of the 1970s and 80s and are in danger of being dismissed as relics of their time. However, I argue that to so view them is mistaken since they act as strong foundations upon which to build a contemporary approach. Evidenced by the enduring nature of the ideas they present, which are still being discussed 30 years later, they offer a significant practical legacy.

## **Section 2 – Definition, Nature and Criticisms of Care**

It is true that the Ethics of Care is by no means ubiquitously lauded as an ethical approach. Indeed, Marian Barnes asks; ‘If care (...) embodies values and practices necessary to human survival and flourishing, why does it not receive universal acceptance as fundamental to policies and practices focused on achieving welfare, well-being and citizenship?’<sup>91</sup> In questioning whether there can even be a distinct Ethics of Care at all, Peter Allmark,<sup>92</sup> contends that its weaknesses are found in first, in its vagueness due its ‘disturbing lack of content’,<sup>93</sup> secondly, in the inadequate analysis of it as a moral concept, and thirdly, in its inability to distinguish between whether our caring efforts are going to the “right” or “wrong” source.<sup>94</sup> In an attempt to address these concerns Allmark’s three criticisms will be used as the basis of the rest of the discussion in this section.

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<sup>91</sup> Barnes (n2) 6.

<sup>92</sup> Peter Allmark, ‘Can there be an Ethics of Care?’ (1995) 21 *Journal of Medical Ethics* 19.

<sup>93</sup> *ibid* 20.

<sup>94</sup> *ibid* 22.

## 2.1 – Defining Care

Whilst Allmark is certainly not alone in voicing concern that ‘care’ can be a vague notion, some commentators have celebrated care’s lack of definition as one of its greatest assets. In refuting Allmark’s criticisms, Ann Bradshaw,<sup>95</sup> claims that the source of care is not found in definition but in practice. She takes as her basis for care the ideas she claims underpin the disciplines of nursing and medicine; that care is ‘no mere ethical discourse or idea; it was incarnated, lived out, practical action’.<sup>96</sup>

Likewise, Peta Bowden resists the temptation to ‘penetrate the essence of care’ by debating its definition, confining herself to claiming that ‘care expresses ethically significant ways in which we matter to each other’.<sup>97</sup> She views the ambiguities of care and the focus on the practical as its strength, in that it is enabled to better cater for the particularities of the situation and recognise ‘the ways in which ethical practices outrun the theories that attempt to explain them’.<sup>98</sup>

Although Bradshaw’s and Bowden’s approaches are appealing in that the subtleties, intricacies and subjectivities of care are best reflected in observing practice, I agree with Nel Noddings that we need to identify behavioural indicators of care in order to entrust, monitor and assign it.<sup>99</sup> There have been a multitude of attempts to define care. One of the most well used and comprehensive definitions is that offered by Joan Tronto and Bernice Fisher who argue that care carries with it vital connotations of both engagement and action.<sup>100</sup> They state that:

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<sup>95</sup> Bradshaw (n57) 8.

<sup>96</sup> *ibid* 8.

<sup>97</sup> Bowden (n5) 1.

<sup>98</sup> *ibid*

<sup>99</sup> Noddings (n10) 12.

<sup>100</sup> Tronto (n2) 102.

On the most general level, we suggest that caring be viewed as *a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible*. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.<sup>101</sup>

Although this definition can be praised for its breadth in extending beyond human beings, beyond the typical dyadic relationship, and for allowing for cultural variation,<sup>102</sup> it can be criticized as being so sweeping as to fall foul to the same criticisms of vagueness that Bowden's and Bradshaw's approaches might merit. Daniel Engster's work is useful here in that he acknowledges the 'objective, material moral foundation' of Tronto and Fisher's definition but seeks to usefully narrow its focus more precisely.<sup>103</sup> He takes a functional trifold approach to care, with the first two aims bearing some similarities to Ruddick's maternal practice. He claims that care is a form of reproductive labour that he defines as 'everything we do directly to help individuals to meet their basic needs, develop or maintain their basic capabilities and live as much as possible free from suffering, so that they can survive and function at least at a minimally decent level'.<sup>104</sup>

I would argue that such a functional definition is lacking without a consideration of the necessary attitude or character traits of care that should accompany the practice. Noddings equates care not primarily with action but rather within the 'pre-act

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<sup>101</sup> *ibid* 103. Emphasis added.

<sup>102</sup> *ibid* 104.

<sup>103</sup> Daniel Engster, 'Rethinking Care Theory: The Practice of Caring and the Obligation to Care', (2005) 20(3) *Hypatia* 50, 51.

<sup>104</sup> Noddings (n10) 54.

consciousness',<sup>105</sup> or universal moral attitude, which takes the form of an internal effort to displace one's own reality and 'apprehend the reality of the other',<sup>106</sup> which then compels us to act in accordance with it.<sup>107</sup> Here also Engster adds a cognitive or character-based element to his definition by noting that care is not only a practice but should be done so according to the 'virtues' of care, which he lists as attentiveness, responsiveness and respect.<sup>108</sup> This combination of the practical and the virtuous, Engster likens to Margaret Urban Walkers synthesis of the 'theoretical-juridical model' and the 'expressive-collaborative' model'.<sup>109</sup> Finally, Ruth Groenhout posits an important expansion to the definition by including not only caring virtues and relational practices but also an analysis of social structures and institutions that support, or fail to support them. I agree with Groenberg that '[a]ll three levels are important, and without any of them our analysis will be incomplete'.<sup>110</sup>

## 2.2 – The Nature and Source of Care

In developing the discussion relating to definition, it is useful to consider whether what is being defined is a concept, a theory or an orientation of care. Some commentators, such as Virginia Held argue that care is indeed a complete moral theory,<sup>111</sup> in the sense that care can be seen as a collection of explanations that can be organized and tested. However, others define it merely as a concept or an unorganized set of ideas.<sup>112</sup> I am persuaded by the arguments of Alisa Carse<sup>113</sup> and Margaret

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<sup>105</sup> *ibid* 28.

<sup>106</sup> *ibid* 14.

<sup>107</sup> *ibid* 16.

<sup>108</sup> Engster (n103) 55.

<sup>109</sup> Walker (n66).

<sup>110</sup> Ruth Groenhout, Interview (6 December 2010) *The Ethics of Care* <[www.ethicsofcare.org/interviews/ruth-groenhout/](http://www.ethicsofcare.org/interviews/ruth-groenhout/)> <Accessed 24 February 2013>.

<sup>111</sup> Held (n1) 4.

<sup>112</sup> Dennis Earl, 'Concepts' *Internet Encyclopedia of Philosophy* <[www.iep.utm.edu/concepts/](http://www.iep.utm.edu/concepts/)> <Accessed 4 March 2013>.

Little<sup>114</sup> that the most fruitful way to view ‘care’ is as a moral *orientation*. Little claims that orientations are not equivalent to moral theories in and of themselves and reading them as theories serves to ‘flatten’ important distinctions, mis-claim their implications but most vitally to obscure what is most transformative about them.<sup>115</sup> Rather, the promise of an orientation is found in its scope beyond a set of beliefs, to encompass areas of concern and discernment, habits and proclivities of interpretation and selectivity of skills.<sup>116</sup>

For Carse, a care orientation is based around relationality, attentiveness to situation and sensitivity to the needs of others and could incorporate values such as empathy, concern and responsiveness as the moral ideal.<sup>117</sup> She makes no claims that this orientation is the sum total of morality and contrasts it with the orientation of justice-<sup>118</sup> claiming that the two can be distinguished by ‘differences in the reasoning strategies employed and the moral themes emphasized in the interpretation and resolution of moral problems (...)’.<sup>119</sup> This in some ways echoes Gilligan’s original treatment of the Ethics of Care, which by using the analogy of the ‘figure perception image’,<sup>120</sup> she claims that far from being mutually exclusive, care and justice are alternative viewpoints albeit ones that cannot be held simultaneously. However,

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<sup>113</sup> Alisa Carse, ‘The “Voice of Care”: Implications for Bioethical Education’ (1991) 16 *Journal of Medicine and Philosophy* 5.

<sup>114</sup> Margaret Olivia Little, ‘Care: From Theory to Orientation and Back’ (1998) 23(2) *Journal of Medicine and Philosophy* 190.

<sup>115</sup> *ibid* 191.

<sup>116</sup> *ibid* 195.

<sup>117</sup> *ibid*

<sup>118</sup> Carse (n113) 6.

<sup>119</sup> *ibid*

<sup>120</sup> This is where for example one might view either a face *or* a vase in the same image but not both at the same time. Gilligan explains ‘the perspectives of justice and care are not, opposites or mirror-images of one-another, with justice uncaring and care unjust. Instead, these perspectives denote different ways of organising the basic elements of moral judgment: self, others and the relationship between them’- see Carol Gilligan, ‘Moral Orientation and Moral Development’ in Eva Feder Kittay and Diana Meyers (eds) *Women and Moral Theory* (Rowman and Littlefield 1987) 22.

Steven Edwards<sup>121</sup> drawing on real life experiences, claims we do seem to combine the two orientations by being partialist with those closest to us but using justice reasoning for distant others.<sup>122</sup> Here, I argue that in the context of ethical decision-making relating to children, it is imperative to begin with the orientation of care, which represents a psychological stance from which to then develop and carry out theory.<sup>123</sup> I agree with Chris Gastmans that it may then be possible to see the Ethics of Care as an orientation over which to lay the kinds of considerations that are associated with principles of justice, such as fairness, autonomy and duty.<sup>124</sup>

In answer to Allmark's second criticism, that the Ethics of Care is devoid of moral source, Ann Bradshaw proposes the Greek concept of *philia*, which she claims developed into the Christian ethic of 'love thy neighbor'. She acknowledges Allmark's objection, by noting that 'care shorn of its original meaning becomes meaningless',<sup>125</sup> and so calls for a return to the traditional Judaeo-Christian understanding of care. In a similar vein Ruth Groenhout has argued that the origins of the natural caring response forming the basis for the Ethics of Care, is found in a theistic framework in which humans are created to care because of the 'fundamental goodness of creation'.<sup>126</sup> However, for those that are not religious it is important to find another moral source for the Ethics of Care, if it is to have the type of broad appeal that will enable it to be used in legal and ethical contexts. Noddings rejected the need for the Ethics of Care to be based upon divine edict or a belief in God<sup>127</sup> but

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<sup>121</sup> Steven Edwards, 'Is there a Distinctive Care Ethics?' (2011) 18(2) Nursing Ethics 184, 187.

<sup>122</sup> *ibid* 188.

<sup>123</sup> *ibid* 200.

<sup>124</sup> Chris Gastmans, 'The Care Perspective in Healthcare Ethics' in AJ Davies, V Tschudin and L de Raeve (eds) *Essentials of Teaching and Learning in Nursing Ethics* (Churchill Livingstone, London 2006) 135-48.

<sup>125</sup> Bradshaw (n57) 9.

<sup>126</sup> Groenhout (n8) 75.

<sup>127</sup> Noddings (n10) 29.

claimed that the ‘wellspring for our ethical behaviour’ lay in the human affective response, something she dubbed a kind of ‘ethical feeling’.<sup>128</sup> I am persuaded by Stan Van Hoof’s ‘deep care’, which provides a plausible explanation for the source of care that is beyond rule, virtue or indeed religious edict.<sup>129</sup> He defines ‘deep care’ as an unintentional force providing impetus for all our concerns, plans and desires, with the fundamental purpose of ‘the formation and maintenance of both the integrity of our selves and also of our relationship with others and the world around us’.<sup>130</sup> He asserts that this deep caring is composed of both ‘being-for-others’ and ‘self-project’, which means that if we care about anyone or thing, ‘it is because deep caring is the very nature of our being’.<sup>131</sup>

### 2.3 – The ‘Who’, ‘What’ and the ‘How’ of Care

Allmark’s third criticism of the Ethics of Care is that it fails to show us who or what to care for or how we should care. However, several advocates have outlined both the obligations and limits of care, with Noddings for example, describing our obligations as consisting of concentric circles. The innermost circle comprises of those we love and who have the greatest claim upon our care, moving outwardly in circles containing those for whom we have regard such as work colleagues, where our conduct will be measured by how we feel, what the other expects of us and what the ‘rules’ of that situational relationship suggest.<sup>132</sup> Noddings also allows for the care of those ‘proximate others’ who are connected by chains to those within our circles of care, such as future in-laws or students.<sup>133</sup>

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<sup>128</sup> *ibid* 3.

<sup>129</sup> Stan Van Hoof, ‘Bioethics and Caring’ (1996) 22 *Journal of Medical Ethics* 83, 84.

<sup>130</sup> *ibid* 84.

<sup>131</sup> *ibid* 85.

<sup>132</sup> Noddings (n10) 46.

<sup>133</sup> *ibid* 47.



Further, care has been identified as parochial in that it necessarily engages with the concrete and the local. Because of this close connection with the particulars of our most intimate relationships, an enduring problem faced by care ethics how to move this focus outwards to the wider world and consider our caring responsibilities to strangers. Noddings certainly has greater difficulty in defining our obligation to the stranger, whom she admits has an uncertain moral claim for care and whom the one-caring may meet with dread as her resources for care grow ever stretched.<sup>134</sup> Indeed because of this critics such as Tim Cockburn have claimed that care is too focused upon the needs of others.<sup>135</sup> Maureen Sander-Staudt has highlighted the criticism that care is a ‘slave morality’,<sup>136</sup> in that it falsely valorises and romanticises care as being an activity of selfless love and sacrifice, which pays no heed either to the interests of the one-caring or the moral limits beyond which care should never be extended. Rosemarie Tong argues that ‘potentially the most devastating’ notion connected with the Ethics of Care is that since justice and care seem to be linked to political descriptions of man as the oppressor and woman as the oppressed, then valorizing care as virtuous, women’s work can only make the position of women worse.<sup>137</sup> Such valorisation of care also serves to obscure the potential ‘dark side’ of caring relationships, a concept which I explore in the Conclusion in relation to the limits of care.<sup>138</sup>

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<sup>134</sup> *ibid* 47.

<sup>135</sup> Tim Cockburn, ‘Children and the Feminist Ethic of Care’ (2005) 12 (1) *Childhood* 71, 81 -83.

<sup>136</sup> Sander-Staudt (n6)

<sup>137</sup> *ibid*

<sup>138</sup> Conclusion.

Although of course, these may all be acknowledged as valid dangers, a mature Ethics of Care will acknowledge that, as Tong claims, ‘There is a *final* limit on caring’.<sup>139</sup> Such a limit may be sought by recognizing the correct balance between care of self and care of others. Tronto notes that in this context, conflicts between competing demands of care and limits to the extent and nature of care can be resolved acknowledging the universal vulnerability of the human condition and by seeking to accommodate ‘the needs of the self and of others, of balancing competition and cooperation, and of maintaining the social web of relations in which one finds oneself’.<sup>140</sup>

### **Section 3 – Solving the Problems: Modern Constructions of Care**

#### **3.1 – Care Theory in the 1990s**

Despite the criticisms relating to the coherence of the Ethics of Care as a moral theory raised above, care advocates in the 1990s continued to refine their approaches and address some of these criticisms. One of the most prominent is Joan Tronto, who in her 1993 monograph argues that the Ethics of Care will only be able to overcome its criticisms and achieve acceptance as a valid moral approach if it moves away from its conceptualisation as a gendered ‘woman’s morality’ and is instead constructed as a comprehensive political theory.<sup>141</sup> She does not discount the idea that the Ethics of Care may have legitimately been identified as a ‘different voice’, however she also makes no claims that care is meant to ‘serve as a total account of morality’.<sup>142</sup> Further, she departs from Gilligan and Noddings in that she seeks to move from an explanation of that difference based on gender to one stemming from social

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<sup>139</sup> Tong (n29) 42.

<sup>140</sup> Tronto (n2) 658.

<sup>141</sup> *ibid* 656.

<sup>142</sup> *ibid* 126.

conditions of subordination due to race, class and education (of which women's experience may have been a part).<sup>143</sup> Tronto argues that although care has been seen as the domain of the powerless, in fact 'it is the enormous real power of care that makes its containment necessary'.<sup>144</sup> She goes on to develop her theory of care in terms of both determinative action and cognitive attitudes, which culminate in the practice of care. She claims that there are four analytically separate but interconnected phases to care:<sup>145</sup> first, 'caring about' which involves recognizing a need and assessing how that need should be met; secondly, 'taking care of' which necessarily involves recognizing something can be done to address the need and assuming responsibility for the required action; thirdly, 'care giving', which involves the direct meeting of care needs by the performance of care labour; and fourthly, 'care-receiving', which is akin to Nel Noddings third stage, in that care must be recognized or responded to. This final stage acts as a method of monitoring whether the care needs have actually be met.<sup>146</sup> She suggests that this activity and its end, which can be measured by compliance with the four phases, set the boundaries of reasonable and successful caring practice.<sup>147</sup>

In conjunction with her four phases of care, Tronto presents four 'ethical elements' of care; attentiveness, responsibility, competence and responsiveness, which integrated as a whole demonstrate the necessary attitudes or virtues which should be present in order for caring to be successful.<sup>148</sup> She acknowledges that there are inevitable conflicts with care and limits beyond which care must not go. In order to overcome

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<sup>143</sup> *ibid* 3.

<sup>144</sup> *ibid* 122.

<sup>145</sup> *ibid* 106.

<sup>146</sup> *ibid* 107.

<sup>147</sup> *ibid* 108.

<sup>148</sup> *Ibid* 128-134.

claims of partiality and parochialism, she turns to a theory of justice to strike a balance between an overly abstract conception of needs, which fails to recognize the cultural, technological and historical context of providing for those needs and too concrete a focus, which may be too inward looking and fail to encompass the needs of those in the wider world.<sup>149</sup> Tronto suggests the creation of ‘objective’ standards for discerning between care needs can be based around Martha Nussbaum’s ‘Human Capabilities’,<sup>150</sup> as the recognition of our dependence upon others in order to develop our fundamentally important capabilities will allow for particularism but avoid the cultural relativism often associated with care.<sup>151</sup> Tronto’s theory is useful in terms of the development of this thesis in that it demonstrates how to move care from the private out into the public arena. It is also successful in clearly outlining and integrating both the practices and the moral attitudes of care. However, her suggestion of using Nussbaum’s ‘human capabilities’ as a way to determine priority in the case of competing needs is not entirely convincing, as she does not clearly demonstrate why we should assume that care should lead to the development of autonomy as a way for us to develop our capacities.<sup>152</sup>

Peta Bowden,<sup>153</sup> has developed an altogether different approach to the Ethics of Care. In her 1997 book, she begins from the familiar point of intuition in claiming the importance of care but she resists the temptation to ‘penetrate the essence of care’ by debating it’s definition or creating a principled care theory. Instead she takes a pluralist approach by seeking to explore the multitudes of ways in which care may be

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<sup>149</sup> *ibid*139.

<sup>150</sup> Martha Nussbaum, ‘Human Functioning and Social Justice: In Defence of Aristotelian Essentialism’ (1992) 20(2) *Political Theory* 202. This approach is discussed in Section 4.2.2 below.

<sup>151</sup> Tronto (n2) 140.

<sup>152</sup> Ann Ferguson, Book Review ‘*Joan Tronto: Moral Boundaries*’ (1996) 13 *Radical Philosophy Review of Books*, 18, 22.

<sup>153</sup> Bowden (n5).

understood and practiced.<sup>154</sup> Bowden claims that the ambiguities or *possibilities* of care in practice, is one of its attractions. She examines the areas of mothering, friendship, nursing and citizenship and claims that ethics are best explored by observing the similarities, differences and ‘plurality of possibilities’ in differently located practices of care.<sup>155</sup> In this sense, Bowden’s account is very much true to care ethics’ original emphasis on practical lived-experience as the epistemological basis for care.

On the other hand, Bowden recognizes the difficulty in particularist, partial and concrete methodology, which may result in care ethicists being mired down in endless descriptions of more and more specific particulars, without ever being able to make a statement that is representative of any individual, let alone a specific group. Bowden attempts to tread a middle ground arguing that orientations that see opposition in the need for gender-sensitive, ethical understandings of care, and the recognition of the plurality of possibilities for care in practice, are misguided.<sup>156</sup> Her approach is useful in overcoming some of the objections to gender essentialism, stereotyping of women’s roles or resolving the debate about the conflict between care and justice. In her discussion of mothering, friendship and nursing she is successful in illustrating how care can be specific to particular institutions or roles. But despite these attractions, it can be argued that Bowden’s plurality is its undoing as it falls foul of the criticism of lack of definition and vagueness.

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<sup>154</sup> *ibid* 2.

<sup>155</sup> *ibid* 12.

<sup>156</sup> *ibid* 12.

### 3.2 - Care in the 21<sup>st</sup> Century

In the 21<sup>st</sup> century care theory has taken many different forms. A particularly insightful, contemporary account of how a paradigm built upon the assumption of interactions between equal, autonomous adults is insufficient to guide the moral decisions made with intimate, unequal, interdependent relationships is found in the work of philosopher Virginia Held.<sup>157</sup> In her 2006 monograph, she takes a sweeping view of the Ethics of Care's applicability from personal relationships through to global issues. She acknowledges the Ethics of Care's relative immaturity and its contingent weaknesses and gaps. However she credits the growth in the interest in normative perspectives, with the resurgence of the interest in care.

Held argues that the Ethics of Care is indeed a complete moral theory, which is both a practice and a value and she insists that it must be a *feminist* ethic, open to both men and women to adopt.<sup>158</sup> She highlights five defining features that most care theories have in common. The first is the focus on the morality of taking care of particular others for whom we are responsible;<sup>159</sup> in contrast to moralities whose basis is the 'independent, autonomous, rational individual'.<sup>160</sup> Secondly, she pinpoints the fact that the Ethics of Care values emotions, such as sympathy, empathy, sensitivity and responsiveness, rather than rejecting them as more traditional moral theories are wont to do. Such emotions are seen to enable actors in interpersonal contexts to assess the best course of action and the Ethics of Care provides the framework to scrutinise and direct such emotions.<sup>161</sup> Thirdly, Held observes that in contrast to the focus of the Ethics of Justice on abstract reasoning and impartiality, the Ethics of Care 'respects

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<sup>157</sup> Held (n1).

<sup>158</sup> *ibid* 20.

<sup>159</sup> *ibid* 10.

<sup>160</sup> *ibid*

<sup>161</sup> *ibid* 11.

rather than removes itself from the claims of particular others with whom we share actual relationships'.<sup>162</sup> Indeed, within the Ethics of Care it is permissible to give preference to the needs and wants of the particular other, even when they conflict with universal norms or rules. The fourth consideration is that the Ethics of Care, as a feminist theory, reconceptualizes the notion of the household being a private sphere, free from governmental interference whilst the public sphere is relevant to morality from the viewpoint of unrelated, independent and equal individuals. Indeed it tackles unequal and dependent relationships found within the family, and then is able to take this out into wider society in relation to inequality of race, religion, class and gender.<sup>163</sup> The final characteristic, is the unique conception of persons, as relational rather than self-sufficient; a person who remains interdependent with others throughout their lives.<sup>164</sup>

Held considers the impact that the Ethics of Justice may have on the Ethics of Care and concludes that justice may have a place in care but maintains the importance of upholding the distinctions between the two approaches. Further, she rejects both suggestions by Darwall<sup>165</sup> that the Ethics of Care can be added on to traditional theories or that it be relegated to the private domain, as originally proposed by Noddings.<sup>166</sup> Held's proposal for how to integrate the concepts of care and justice are to keep them conceptually separate but designate the areas in which they are to have priority. She uses the law, as an example of where justice should have priority but without being devoid of care, and family, as an example of where care reigns supreme. The realms in the middle will call for a careful balancing and consideration

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<sup>162</sup> *ibid* 11.

<sup>163</sup> *ibid* 13.

<sup>164</sup> *ibid* 14.

<sup>165</sup> Stephen Darwall, *Philosophical Ethics* (Westview Press 1998).

<sup>166</sup> Held (n1) 16.

of both approaches but with the underlying claim that care should provide the wider and deeper ethics within which justice should be sought as ‘there can be no justice without care (...) for without care no child would survive and there would be no persons to care about’.<sup>167</sup>

Another contemporary paradigm is to link care with virtue ethics; with probably the most well-known advocate being Michael Slote.<sup>168</sup> He proposes an agent-based form of virtue ethics, which treats the moral status of acts as entirely derivative from the fundamental characteristics of motives, traits or individuals, rather than from actions. Slote draws on the notion of benevolence, albeit in a particularistic sense as a possible ground for an agent-based ethical theory.<sup>169</sup> He examines Noddings’ model, which he initially suggests might be an agent-based virtue ethic because of her emphasis upon the innate moral goodness of care but concludes that her focus on the actions of promoting a caring world are more in line with consequentialist thought. Slote also raises concerns about the absence of self-care in many of the early approaches and notes the irony in creating a new ethics that focuses on areas of feminine thought and activity which have typically been used to restrict women’s freedom and self-fulfillment.<sup>170</sup> He resolves this tension effectively, by proposing a model where it can be said that it is best and most admirable to be motivated by concern for others in balance with self-concern, and that all and only actions consonant with such a balance are acceptable.

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<sup>167</sup> *ibid* 17.

<sup>168</sup> Michael Slote, ‘Agent-based Virtue Ethics’ in Michael Slote and Roger Crisp (eds) *Virtue Ethics* (OUP 1997).

<sup>169</sup> *ibid* 256.

<sup>170</sup> *ibid* 257.



In contrast, Eva Kittay has rejected the contention that care is a virtue because care is not only a motive but, as Noddings' has claimed, must be 'completed in the other' through caring action. She argues that if care was a virtue then 'the state of the actor is always sufficient to determine the moral worth of an action'<sup>171</sup> - yet this alone is insufficient. Although there does appear to be a connection between the trait aspect of the definition of care and virtue theory, I agree with Virginia Held that there is a clear difference. Virtue theory focuses upon the development of the virtuous character of a particular individual whereas the ethics of care is distinct in particular, by its emphasis upon *relationships* rather than personal characteristics, *per se*.<sup>172</sup>

Finally, Jonathan Herring has presented a very recent critique that is directly applicable to the law,<sup>173</sup> and ties in with much of the discussion in Section 4, below. Writing elsewhere, I note Herring's claim that that care is at once ubiquitous in life yet largely ignored within the law.<sup>174</sup> He posits clichéd images of a private world of carers who are downtrodden, impoverished, and marginalised, against the public world of society and the law, which is focused on 'precise disputes' concerning economic value, autonomy, and liberty and argues that such presumptions lead to the misguided notion that care and the law are incompatible.<sup>175</sup> Instead he contends that 'caring is an essential aspect of human existence'.<sup>176</sup> Herring like Tronto and Held seeks to categorise the nature of care by presenting four 'Markers of Care', the presence of which he claims provide an indication of the extent to which an

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<sup>171</sup> Eva Feder Kittay, 'The Completion of Care' in *Proceedings of a Workshop on an Ethics of Care: The Normative Complexity of Care* (2010) Rome, Norwegian Institute, University of Oslo (Unpublished) 9-10, cited in Edwards (n211).

<sup>172</sup> Held (n1) 4.

<sup>173</sup> Jonathan Herring, *Caring and the Law* (Hart 2013).

<sup>174</sup> Kirsty Moreton, 'Jonathan Herring: Caring and the Law' (2014) 22(3) *Medical Law Review* 452. The contents of this paragraph are taken from this published work.

<sup>175</sup> Herring (n173) 2.

<sup>176</sup> *ibid*

activity is care or not.<sup>177</sup> The first marker ‘meeting needs’ draws on Joan Tronto’s distinction between ‘caring-about’ and ‘caring-for’ to argue that caring relationships should necessitate caring action which is successful in meeting needs.<sup>178</sup> The second marker is ‘respect’, which in many ways echoes Nel Noddings’ ‘Engrossment’ and ‘Motivational Displacement’. The third marker ‘responsibility’ flags up the element of reliance in the caring relationship and the onus to care even when it is difficult or inconvenient. The final marker is ‘relationality’, which attempts to address the disability critique concerning the assumption that care can ‘cure’ the disadvantages that flow from disability. Confronting the traditional power imbalances found when parties are viewed as ‘carer’ and ‘cared-for’, Herring conceives of caring relationships as multi-directional wherein both may be carers and cared-for simultaneously. Writing elsewhere, I contend that Herring’s approach, while interesting, may be criticised as being both too broad and too idealistic. He is right to be alert to the danger that such breadth may rob his markers of meaning within a legal context. Although it appears that the primary aim in establishing the ‘four markers’ is to flag up the type of care that would be worthy of state support, and he acknowledges that he is presenting care ‘at its best’ and his concession that activities lacking these markers are not necessarily uncaring, somewhat undermines the strength of his model.

## **Section 4 – Care and the Law**

Whilst there has been some progress in applying the Ethics of Care within the context of legal theory, this has been less successful than in areas such as politics and social policy, due to two main difficulties. The first is reflected in the claim by Held that the Ethics of Care by its nature should stand apart from the law and is incompatible with

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<sup>177</sup> *ibid* 14.

<sup>178</sup> *Ibid* 15

the principled, rule-based, justice orientated approach that the law demands.<sup>179</sup>

Noddings characterizes this principle-based approach as having a ‘contemporary mathematical appearance’, which she claims reflects the ‘language of the father’ and thereby moves legal considerations beyond the ‘sphere of human activity and the feeling that pervades such activity’.<sup>180</sup>

I share Ruth Groenhout’s acknowledgment of the significant difficulty in constructing a moral theory that is as particularist as care is deemed to be, in the pluralistic public sphere where the perceived need for universal principles is prime.<sup>181</sup> Nonetheless, I affirm that this difficulty can be overcome. I agree with the argument made by Held above, that Care Ethics is the starting point of choice. However I am not convinced by her notion that the domains of care and justice should be prioritized in different spheres of life. Rather my conception is one where the basis of care may be overlaid with an orientation of justice to present the richer, more complete approach that is often required by the law. Further, I concur with Groenhout that the Ethics of Care does not need to be suitable for all areas of public life, or indeed the law, in order to be useful but should be ‘evaluated on its own merits, based on the insights that it can offer and the light it can shed (...)’.<sup>182</sup> I argue that these insights mean that it is uniquely well positioned for use in areas such as Family and Healthcare Law, both because of its power to accurately describe the rationale for legal interventions here and its normative strength in highlighting how decision-making in these areas ought to be made.

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<sup>179</sup> *ibid* 17.

<sup>180</sup> Noddings (n10) 1.

<sup>181</sup> Groenhout (n12) 181.

<sup>182</sup> *ibid* 182.

The second problem resides in the construction of the legal subject. The traditional portrayal of the equal, independent, autonomous legal subject appears to be at odds with the complex relationality posited by the Ethics of Care. Indeed, I am persuaded by Martha Fineman's assertion that the autonomous subject is myth.<sup>183</sup> Human experience, and the law that is constructed to regulate and arbitrate that experience, is inherently relational. Therefore, I would assert that the adoption of a care orientation within the law best captures the reality and value of our experiences as vulnerable, embodied and interdependent, and as Rosie Harding asserts, provides for a more nuanced legal subject.<sup>184</sup>

#### 4.1 – The Law and the Particular

##### 4.1.1- Reconciling Care and Justice

To resolve the problem that the Ethics of Care may be insufficient on its own as an ethical theory for use within the law, Louise Campbell-Brown has proposed an integrated care and justice model in which the traditional justice principles of fairness and equality may act to provide structure for the Ethics of Care.<sup>185</sup> This may be seen as akin to Tronto's proposal that a theory of justice may be used to temper the reach of care. Justice can be used to discern between competing needs, by striking a balance between an overly abstract conception of them, which fails to recognize the cultural, technological and historical context of providing for those needs, and too concrete a focus which may be too inward looking and fail to encompass the needs of those in the wider world.<sup>186</sup>

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<sup>183</sup> Martha Albertson Fineman, 'The Vulnerable Subject: Anchoring Equality in Human Condition' [2008] 20 Yale Journal of Law and Feminism 1.

<sup>184</sup> Rosie Harding, *Duties to Care: Dementia, Relationality and the Law* (CUP 2017).

<sup>185</sup> Louise Campbell-Brown, 'The Ethic of Care' [1997] UCL Jurisprudence Review 272. 280.

<sup>186</sup> Tronto (n2) 139.

I concede that in the context of the law there needs to be a way of resolving conflict and delimiting practices or decisions that would be legally unacceptable. Given that I have claimed that care is best viewed as a moral orientation or psychological stance from which to develop theory,<sup>187</sup> a fruitful reconciliation between care and justice might result from viewing justice as an alternative orientation- each to be utilized at different times and for different purposes.<sup>188</sup> Carse claims that these orientations can be distinguished by ‘differences in the reasoning strategies employed and the moral themes emphasized in the interpretation and resolution of moral problems (...)’.<sup>189</sup>

This notion of different themes harkens back to Gilligan’s alternative gestalts of justice and care, which she claims ‘are not, opposites or mirror-images of one-another, with justice uncaring and care unjust’.<sup>190</sup> Little takes up the theme by defining how the elements of self, others and relationship might be ordered under these two orientations.<sup>191</sup> She characterizes the justice gestalt as marked by an atomistic self, others viewed as potentially oppressive and a default stance towards relationship of mistrust.<sup>192</sup> In contrast, the care gestalt presents an interconnected self, relatedness in its particularity as the natural state and a default stance of trust in relationships.<sup>193</sup>

I contend that in the context of legal and ethical decision-making relating to children, it is imperative to begin with an orientation of care, as this would more accurately

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<sup>187</sup> Little (n114) 200.

<sup>188</sup> *ibid*190.

<sup>189</sup> Carse (n113) 5.

<sup>190</sup> Carol Gilligan, ‘Moral Orientation and Moral Development’ in Eva Feder Kittay and Diana Meyers (eds) *Women and Moral Theory* (Rowman and Littlefield 1987) 22.

<sup>191</sup> Little (n114) 198.

<sup>192</sup> *ibid* 199.

<sup>193</sup> *ibid*

reflect the reality of most children as being interconnected, benefiting from close relations with others - especially parents, and beginning from a presumption of trust within those relationships. Of course, there may be cases where the particularity of the child's reality may reveal a disconnected self, dysfunctional relations with others or a breakdown of relationship. In these instances Chris Gastmans' suggestion is helpful, in that it may be possible to lay over a care orientation the kinds of considerations that are associated with principles of justice, such as fairness, autonomy and duty, as a form of corrective action.<sup>194</sup> Manning has termed this 'just caring';<sup>195</sup> where care and justice act in terms of 'each perspective informing the other and transforming the whole'.<sup>196</sup> Given that I have argued that care should come first, I prefer the term 'Caring Justice' and I contend that such a concept may work well in respect of this thesis, as the case studies in Chapters 4-6 will be examined from the perspective of both family and healthcare professional, and the law.

#### 4.1.2 - Accommodating the Particular

In the search for how to accommodate the level of particularism required by care within a legal framework, Martha Minow's work is helpful. She was one of the first legal scholars to challenge the presumptions that underlie the rigid categorisations that underpin the American legal system and sites this discussion around the quest for equality within the law.<sup>197</sup> She compares the impact of the 'formal equality option'<sup>198</sup> - with its risks of minimizing differences that really do matter, with the 'substantive

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<sup>194</sup> Chris Gastmans, 'The Care Perspective in Healthcare Ethics' in AJ Davies, V Tschudin and L de Raeye (eds) *Essentials of Teaching and Learning in Nursing Ethics* (Churchill Livingstone, London 2006) 135-48.

<sup>195</sup> Rita Manning, *Speaking from the Heart: A Feminist Perspective on Ethics* (Rowman and Littlefield 1992) Chapter 4.

<sup>196</sup> Koggel (n19) 6.

<sup>197</sup> Martha Minow, *Making All The Difference: Inclusion, Exclusion and American Law* (Cornell University Press, New York 1990).

<sup>198</sup> Koggel (n19) 1

equality option of “special” treatment”,<sup>199</sup> - which thereby risks the labeled party becoming negatively stereotyped by the label. She reasoned that this resulted in the paradox of the ‘dilemma of difference’<sup>200</sup> that the law faces in seeking to ‘ameliorate unfair consequences to the powerless without further reducing their power’.<sup>201</sup>

This insight reflects the difficulties the law faces in utilising a model based on the Ethics of Care, which first arose from feminist observations that women’s moral experience was treated as ‘difference’ and their voice unheard by the dominant male power-base. On the one hand the recognition of this ‘difference’ gave a space for women’s experiences to be recognized and validated, when they had previously been largely over-looked. Yet the temptation in seeking this form of ‘equality’ is to squeeze care experiences into a preexisting mold, as illustrated by Gilligan’s mirroring of Kohlberg’s hierarchal structure in her own model, or to fall into the trap of gender essentialism as detailed by Drakopoulou below. Both risk negating some very distinctive features, such as the central focus on relationships, which make the care orientation unique. But the paradox is exposed in the act of labeling the Ethics of Care as a ‘different’ approach, which lends credence to some unspoken assumption that principle-based justice reasoning by the autonomous subject should be the norm and that care thinking (and by implication women’s thinking) is thereby viewed as ‘less-than’ or ‘alternative’. As Christine Koggel notes, this traditional binary approach of sameness/difference to accommodating variation within the law, is a symptom of the ‘limited understanding of human relationships’<sup>202</sup> within the justice orientation,

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<sup>199</sup> *ibid.*

<sup>200</sup> Minow (n197) 20.

<sup>201</sup> Judith G McMullen, ‘Book Review: *Martha Minow, Making all the Difference*’ (1991) 74(2) *Marquette Law Review* 253.

<sup>202</sup> Koggel (n19) 3.

which allows for neither a reexamination of the unquestioned norms nor the accompanying assimilation into preexisting structures.<sup>203</sup>

#### 4.1.3 - An Ethic Structured around Roles and Responsibilities

Although I acknowledge that much of law is relational and therefore that the Ethics of Care may shed new light when used as a normative ethic in areas such as contract and criminal law, commentators such as Fiona Kelly have questioned ‘whether it would make sense’ in areas of the law outside of those that deal with the obviously domestic.<sup>204</sup> Kelly’s reservation may be due to the historical fact that the original feminist critique has largely focused on the personal and familial. Nonetheless, it appears true that the Ethics of Care is uniquely well placed as both a descriptive *and* normative ethic in areas such as Healthcare and Family Law. As a descriptive ethic, I argue it reveals the rationale of much of the regulation and judicial reasoning within Family Law, which is necessarily framed around intimate relationships, and Healthcare Law, which is explicitly concerned with ‘regulating embodied states’.<sup>205</sup> The Ethics of Care may also act as a powerful normative force, by for example, aiding the interpretation of the ‘best interests’ test<sup>206</sup> in cases involving the welfare of a child, by enabling a view of the ‘cared-for’ as first and foremost embodied, relational and interdependent.

Furthermore, adopting a care orientation might not only carry particular force in certain areas of the law but also regarding specific roles played by, and

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<sup>203</sup> *ibid* 2.

<sup>204</sup> Fiona Kelly, ‘Conceptualising the child through an ‘Ethic of Care’: Lessons for Family Law (2005) 1(4) *International Journal of Law in Context* 375,394.

<sup>205</sup> Ruth Fletcher, Marie Fox and Julie McCandless, ‘Legal Embodiment: Analysing the Body of Healthcare Law’ (2008) 16 *MLR* 321,322.

<sup>206</sup> The Children’s Act 1989 s1.



responsibilities borne by medical or legal professionals in their decision-making capacity. Sean Cordell's work recognizes the pervasive nature of the normative force of social and professional roles and advocates an approach to morality that is role specific.<sup>207</sup> He uses a neo-Aristotelian account of the link between a virtuous character and right-action to consider moral action in the context of particular social roles, and proposes a model which attends to both the qualities of institutions as well as the character of actors by appeal to the characteristic activity of the institution.<sup>208</sup>

His observation is pertinent in that sometimes the responsibilities of a particular role are not specified or codified, such as those of a parent, but rather are gleaned from the observation of good practice. This links in with those arguments that care thinking arises primarily from engagement in actual care practice.<sup>209</sup> Cordell advocates a view based upon the function of institutions by discerning the purpose for which the characteristic activity of the institution was made and using this as a measure to assess its ethical compliance.<sup>210</sup> He argues that this is to be done by connecting the particular institution with a specific set of human goods with which it is concerned; so for example the judiciary are concerned with justice, the medical system with health and parents with responsibility. This may be a novel application of the Ethics of Care wherein the obligation to care may be posited as the prime orientation but that the way in which that responsibility is interpreted in its particulars may be dependent upon the specificity of the role or institution involved. For this thesis, this might result in bringing together perspectives of 'caring responsibility' from parents (and

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<sup>207</sup> Sean Cordell, 'Virtuous Persons and Social Roles', (2011) 42(3) *Journal of Social Philosophy* 254.

<sup>208</sup> *ibid* 255.

<sup>209</sup> Ruddick (n9) and Held (n1).

<sup>210</sup> Cordell (n207) 265.

children), ‘caring justice’ from the judiciary and ‘caring healthcare’ from the professionals, to form a more holistic approach to decision-making.

## 4.2 - Reconstructing the Legal Subject

### 4.2.1 - The Crisis of Subjectivity

The second difficulty the law has faced in embracing the Ethics of Care is in the construction of a legal subject that can accommodate the particularity and interrelatedness demanded by care. Maria Drakopoulou has identified the intractable problem of the ‘crisis of subjectivity’<sup>211</sup> in relation to attempts to fit the diversity of *women’s* experience into the ‘straitjacket of a unitary legal subject’.<sup>212</sup> She charts the three phases in this crisis from the attack on the jurisprudence of liberal individualism and presumptions of ‘formal equality’;<sup>213</sup> through the attempt to endow the legal subject with distinct female constitutive elements that fell prey to gender essentialism; to the current shift in focus away from the subject to the Legal System itself. Here she claims, the Ethics of Care is now understood as ‘relational jurisprudence’ - a special kind of normative practice ‘disassociating itself from a feminine mode of reasoning and judgment, divesting itself of any particular subject before the law (...)’.<sup>214</sup>

Across all three phases Drakopoulou rejects the Ethics of Care as failing to deliver on its promise to solve this crisis due to its lack of delimitation of rationale, objectives or legitimacy.<sup>215</sup> Yet I differ with Drakopoulou in her interpretation of and

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<sup>211</sup> Maria Drakopoulou, ‘The Ethic of Care, Female Subjectivity and Feminist Legal Scholarship’ (2000) 8 *Feminist Legal Studies* 199.

<sup>212</sup> *ibid* 200.

<sup>213</sup> *ibid* 211.

<sup>214</sup> *ibid* 216.

<sup>215</sup> *ibid* 207.

dissatisfaction with ‘relational jurisprudence’. She decries this transformation as moving from a concern with the specificity of the female condition to ‘a truly human justice, with benefits accruing to everyone, not only empirical women’,<sup>216</sup> yet I would argue that in order for the Ethics of Care to be successfully used in the legal arena it must indeed be applicable and accessible to all legal subjects. Her challenge that a decision must be made as to whether to abandon the modern idea of a feminist project in law or insist on project whose validity and legitimacy lies in reconstruction of legal knowledge specifically for the benefit of women is too stark. Rather, I see the current construction of the Ethics of Care as successful in both maintaining its roots within women’s experience but also adept at revealing the true relational nature of the law and thus the necessity for the construction of the relational legal subject.

#### 4.2.2 - Associated Concepts: Trust and Vulnerability.

There are certain concepts that I contend are akin to the notion of care and their incorporation into care theory can be useful in developing and fleshing out our understanding of care in a legal context. Annette Baier’s work offers another perspective from which to consider the Ethics of Care. She contends that an ethic appealing to women might be based upon an ethic of love, coupled with the concept of responsibility.<sup>217</sup> She claims that this ethic of love should be acceptable to both reflective women and men, and that theoretical completeness can be achieved by connecting love with the male preoccupation of obligation, through the medium of trust as it ‘nicely mediates between reason and feeling’.<sup>218</sup> She concludes that

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<sup>216</sup> *ibid* 219.

<sup>217</sup> Annette Baier, ‘What do Women want in a Moral Theory?’ in Roger Crisp and Michael Slote(eds) *Virtue Ethics* ( OUP 1997) 263.

<sup>218</sup> *ibid* 271.

ultimately the relationship between trust, *love* and *feeling* is easier for *human beings* to understand than is the relationship between trust, obligation and reason.

Rosemarie Tong argues that Baier's work is different from the other care theorists in that she more explicitly moves out of the intimate domestic realm into feminist political territory.<sup>219</sup> Baier argues that trust relationships are the proper moral paradigm for good moral choices, because the essence of trust is relying on another person's good will, even at the risk of misplaced confidence; we give up security to gain greater security.<sup>220</sup> She defines the importance of trust as rooted in the concept of human vulnerability and interdependency, concepts that have subsequently been developed in the work of Martha Fineman, as discussed below.

Baier assesses carefully specified relationships in order to establish how trust operates between the parties. She enters familiar 'care' territory navigated by Ruddick and Noddings by drawing upon the 'primate and complete' trust that a baby has in her parents, as an example of the nature of the trust that those within relationships need to develop. But what is most compelling about her argument is that she uses this paradigm to assess how trust (or care) could operate within the public sphere. Starting from the point of 'infant trust' – the natural and non-voluntary trust between unequals,<sup>221</sup> she presents a unique picture of 'persons' in the political world. She claims that 'persons essentially are *second* persons (...) heirs to other persons who formed and cared for them'.<sup>222</sup>

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<sup>219</sup> Tong (n29) 42.

<sup>220</sup> Baier (n217) 275.

<sup>221</sup> *ibid* 248.

<sup>222</sup> Annette Baier, 'Cartesian Persons' in Annette Baier, *Postures of the Mind: Essays on Mind and Morals* (University of Minnesota Press, Minneapolis 1985) 84-6.

This notion of second persons is intriguing and powerful one, as it is a clear departure from the traditional claim that moral maturity is marked by independence and autonomy. Although, Baier acknowledges the necessity of such traits in certain aspects of public life, she argues that as citizens we are only conditionally autonomous and self-sufficient and that such a portrayal of ‘persons’ is an artificial abstraction from our interpersonal dependencies.<sup>223</sup> In this sense care must come first, as Peta Bowden has noted:

(...) for any citizen interactions to take place at all – even ‘a word of each against each’ every citizen must have been nurtured and cared for by others to survive his or her infancy. Without appropriate responses to infants’ survival demands, future citizens would simply die.<sup>224</sup>

Baier argues that the values found within the public justice orientation must ultimately borrow from the relations of parental caring which enable children to experience trust by being cared for. She argues that a willingness to participate in the impersonal trust relations of the public world is encouraged by the sense of participation in a personal climate of trust found within caring relationships.<sup>225</sup> This sense of trust (but always with the caveat that such trust should be ‘appropriate’ and not ‘blind’<sup>226</sup>) then facilitates understanding of and participation in, contractual relations, social responsibility and an acknowledgement of obligations towards fellow citizens ‘if the just society is to last beyond the first generation’.<sup>227</sup> Much like Ruddick, Baier also acknowledges that this parental training is shaped by a close link

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<sup>223</sup> Bowden (n5) 148.

<sup>224</sup> *ibid.*

<sup>225</sup> Baier (n217) 245.

<sup>226</sup> *ibid* 241.

<sup>227</sup> Bowden (n5) 149.

with societies expectations of how human flourishing should include an appreciation of 'public values'.

Finally Baier's conception of self as 'second persons' formed from the love and trust of others, helps us to appreciate how care can be the overarching theme of morality within which it is possible to construct moral theories to suit the political ends of society. Her focus on the importance of trust, helps to illustrate that the public/ private divide is a false one, as we are all by our very natures interdependent and vulnerable and that the concept of moral maturity as an self-sufficient autonomous individual operating in the public sphere, is an artificial abstraction from the reality of interrelation.

Martha Fineman's work has successfully engaged with the notion of the relational legal subject. She argues that the presentation of the autonomous subject in liberal politics is a myth, stemming from a misunderstanding of the human condition.<sup>228</sup> Indeed, Sean Coyle notes that the autonomous subject was one that even Kant saw merely as an 'aspirational character'.<sup>229</sup> Instead, Fineman presents us with the 'vulnerable' subject, which is far more representative of the human condition and the reality of our lived experience than the autonomous subject.<sup>230</sup> She roots her notion of vulnerability in the fact of embodiment, with the attendant and ultimately uncontrollable risk of harm, injury or, susceptibility to natural disasters. However, she frees vulnerability from the negative connotations of deprivation or victimhood and

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<sup>228</sup> Martha Albertson Fineman , 'The Vulnerable Subject and The Responsive State' [2010] 60 Emory law Journal 251, 255.

<sup>229</sup> Sean Coyle, 'The Human Condition and The Liberal Order' (30 November 2011) Jurisprudence Jotwell , <[juris.jotwell.com/the-human-condition-and-the-liberal-order/](http://juris.jotwell.com/the-human-condition-and-the-liberal-order/)> Accessed 5 March 2013.

<sup>230</sup> Fineman (n183) 2.

instead envisions it as a description of ‘a universal, inevitable, enduring aspect of the human condition’.<sup>231</sup>

However, in practice I would argue that in some ways the approach of Fineman and the Ethics of Care depart. In the realm of liberal politics, Fineman focuses on the problem of equality and uses the image of the vulnerable subject as a prod for state institutions to take action to, if not eliminate, then to ‘mediate, compensate and lessen our vulnerability (...).’<sup>232</sup> Yet I would argue that the Ethics of Care has a far more nuanced relationship with vulnerability. At its most basic level, the purpose of practical care-giving may indeed be attempting to ameliorate the ‘cared-for’s’ vulnerabilities. However, the experience of living in relation actually exposes us to vulnerabilities that may not otherwise be faced, such as the vulnerability of the ‘one-caring’ to exploitation, or of the ‘cared-for’ to abuse. Finally at its most subtle level the Ethics of Care seems to cherish or celebrate the vulnerabilities which are inherent to being open to growth and change and which foster the kind of trust relationships that Baier argues are the proper moral paradigm for good moral choices; where we give up security to gain greater security, ‘exposing our throats so that others become accustomed to not biting’.<sup>233</sup>

### **Section 5 - Jo Bridgeman’s ‘Relational Responsibility’.**

Jo Bridgeman offers a contemporary account of how adopting an Ethics of Care orientation may work particularly within healthcare law and specifically for use with

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<sup>231</sup> *ibid* 8.

<sup>232</sup> Fineman (n228) 269.

<sup>233</sup> Annette Baier, ‘What do Women want in a Moral Theory?’ in Roger Crisp and Michael Slote (eds) *Virtue Ethics* (OUP 1997) 263, 275.

children.<sup>234</sup> She seeks to build a framework that avoids the traditional adversarial focus that pits parents and children against each other and the courts, and by so doing rejects either a rights, or a duties based approach. Instead, she proposes a model of ‘relational responsibility’, which she claims would dismantle current assumptions about the parent-child relationship.<sup>235</sup> Her work is particularly pertinent to this thesis, as it will form the basis for a framework that I will present in Chapter 2. In this chapter I will explain the guidelines as Bridgeman originally constructed them, which is with a sole focus on young children without the capacity for involvement in decision-making.<sup>236</sup> In Chapter 2 I will I will expand and develop them for use with children in mid childhood.

Bridgeman’s framework is composed of three ‘normative guidelines’. Guideline One is ‘attentiveness to the child as an individual with particular needs, wants and concerns’.<sup>237</sup> It may appear that here Bridgeman is invoking a focus on the liberal individualism of autonomy, which would be at odds with the relationality of the Ethics of Care. However, I would interpret this guideline as requiring our first consideration to be the ‘self’ of the child in the *particularity* of his circumstances. This would require Noddings engrossment<sup>238</sup> on the part of decision-makers in order to discern the self of the interconnected, vulnerable and embodied child. The reference to the child’s needs, wants and concerns, can lift him from being the object of care, to being self-determining, both in his responsibility of reciprocation as a ‘cared-for’ but also with the potential of being ‘one-caring’ himself within the caring relation.

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<sup>234</sup> Bridgeman (n2).

<sup>235</sup> *ibid* 44.

<sup>236</sup> Bridgeman defines ‘young children’ as up to about the age of four or five.

<sup>237</sup> *ibid* 44.

<sup>238</sup> Noddings (n10).



Guideline Two is a ‘consideration of the history of caring practices focusing on the quality of the relationships and the expertise gained through actual caring’ by parents and healthcare professionals.<sup>239</sup> This second step takes the Ethics of Care outside of the self of the child to view the value and quality of the caring relation and impact that it has on others. By examining the impact of Nodding’s ‘Motivational Displacement’,<sup>240</sup> the actual care given by parents and healthcare professionals can be assessed. Here the work of Ruddick, Held and Bowden<sup>241</sup> demonstrates how the concrete practical experience of care can be used as a source of expertise, not only in the immediate moment of the decision-making but also to ascertain the longer term consequences for the caring relationship and those surrounding it. Further, external factors which influence the caring relationship may be considered such the capacities, resources and limits of the ‘one-caring’.

Guideline Three is the ‘consideration of the social context of the care, such as cultural norms, beliefs and access to resources needed for care’.<sup>242</sup> This final guideline provides for a broader perspective beyond that which has traditionally informed ‘best interests’, by assessing the decision’s impact in it’s cultural, religious or social context. This guideline may also allow for the space for judges to switch to a justice orientation to temper any overbearing consequences of the intimate caring relationship, to adjudicate between competing care claims, to ensure the protections of

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<sup>239</sup> Bridgeman (n2) 44.

<sup>240</sup> Noddings (n10).

<sup>241</sup> Ruddick (n9), Held (n1), and Bowden(n5).

<sup>242</sup> Bridgeman (n2) 239.

concepts such as fairness and equality or to recognize ‘the limits that may be placed on care due to external factors’.<sup>243</sup>

## **Concluding Thoughts**

In conclusion, this exploration of the genesis and development of the Ethics of Care and its compatibility with the Law forms the theoretical basis for the rest of my thesis. It provides the first stage in demonstrating that the Ethics of Care can indeed provide a suitable ethical, and workable normative framework that may be used within Healthcare Law and Policy to inform the decision-making process relating to children. Each of the early approaches to the Ethics of Care explored in this section has elements that can be utilized in a contemporary theory of care. In Gilligan, we see the identification of an alternative way of moral thinking and the scope for considering how things may be different if we free ourselves from the constraints of viewing the singular justice approach as though it encapsulated all of morality. From Ruddick, we can learn that certain concrete practices, roles and responsibilities may give rise to unique modes of thinking about moral problems. Within Noddings’ work we discover that care can move from observation, orientation and thought into moral *theory*. Her work shows us not only how the roles of those involved within caring relationships may operate but that the concept of care can be taken outside of the sphere of intimate relationships into the public world by profoundly demonstrating that all of life is relational.

The more recent approaches to care demonstrate how some of the limitations and criticisms of early care theory can be overcome. Reflecting upon the Ethics of Care in

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<sup>243</sup> *ibid* 240.

conjunction with the Law provides the opportunity to consider how the law can accommodate the level of particularity that care demands. This presents us with a new view of 'caring justice' - where every person can become a 'cared for' if not in terms of equal attention, at least in the spirit of fairness in relation to the particulars of the situation. Partiality can be tempered by mechanisms of justice, which summon 'ethical care' in scenarios where we move from the ease of 'natural caring' to those where we are required to relate morally to others to whom we are naturally disinclined, or we see as 'undeserving' of such care. When considering the type of legal subject that care envisions I have demonstrated how associated concepts such as capabilities, trust and vulnerability are able to add the depth necessary when care alone is insufficient. Finally, these ideas are drawn together in the consideration of Jo Bridgeman's relational responsibility as it relates to children's healthcare - decision making. I contend that adopting this approach would embolden both children and families, and those holding institutional roles, such as healthcare professionals and judges, to take ethical stances that resonate with the realities of their responsibilities and best facilitates the involvement of the child themselves in their own treatment decisions. Further, it allows for a more authentic portrayal of the inherent relationality of the law and provides for a legal subject that more closely matches the vulnerable, embodied, interconnectedness that is the reality of the mortal condition.

## **CHAPTER 2**

### **CONCEPTUALISATION OF THE CHILD IN MID-CHILDHOOD**

*‘A more realistic and respectful understanding of reason, instead of seeing it as clouded and distorted by emotion, is to see that feeling. Memory and imagination can be sources of great insight. In some ways, the child who is treated has a much deeper understanding of the treatment than the adult administering it’.*<sup>1</sup>

#### **Introduction**

Understanding how mid-childhood, and the child that inhabits it are conceptualised is important in order to make sense of the legislative provisions and case-law surrounding children’s healthcare and decision-making. However, childhood can be seen as a ‘concept in flux’.<sup>2</sup> There is no fixed definition of what it means to be a child or what distinguishes the child from the adult. Indeed ‘many children exceed many adults in size, strength, intelligence and in certain types of experience (...)’.<sup>3</sup> Whilst Flekkoy and Kaufman note that ‘childhood’ did not arise as a special conception until the 17<sup>th</sup> century,<sup>4</sup> disciplines ranging from philosophy, sociology, psychology and

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<sup>1</sup> Priscilla Alderson and Jonathan Montgomery, *Health Care Choices: Making Decisions with Children* (Institute for Public Policy Research 1996) 8-9.

<sup>2</sup> Jonathan Herring, *Family Law* (5<sup>th</sup> edn, Pearson Education Ltd 2011) 397.

<sup>3</sup> Priscilla Alderson and Mary Goodwin, “Contradictions within Concepts of Children’s Competence” (1993) 1 *International Journal of Children’s Rights* 303, 307.

<sup>4</sup> Malfrid Grude Flekkoy and Natalie Hevener Kaufman, *The Participation Rights of the Child: Rights and Responsibilities in Family and Society* (Jessica Kingsley Publishers 1997) 15.

biological science have constructed ‘the child’ in ways that have influenced and impacted upon the law, and in turn upon the place of children within healthcare decision-making.

In spite of this disparity, Heather Montgomery claims that two key findings constantly arise within studies of childhood – ‘firstly, that childhood is a social phenomenon and, secondly, that biological immaturity is assigned social meanings dependent upon the cultural setting’.<sup>5</sup> Yet, inside this social and cultural construction there may coexist a number of conflicting or contradictory discourses within legal, temporal and spatial boundaries.<sup>6</sup> For instance, taking a Western perspective, the child has variously been viewed as the property of his parents; as a “little devil” tainted by original sin and in need of harsh discipline;<sup>7</sup> as the possessor of a “savage” nature, less developed or refined than that of the rational adult;<sup>8</sup> as a “natural child” defined by innocence and purity, set apart from adults;<sup>9</sup> or as an unfinished ‘*becoming*, an incipient being, a person in the process of formation’.<sup>10</sup> However, what each has in common is a conception of the child as an object whose vulnerability and ignorance call for his welfarist protection. In contrast, the ‘New Sociology of Childhood’<sup>11</sup> presents the child not as a ‘becoming’ but rather as a “being”, whose experiences, opinions and

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<sup>5</sup> Heather Montgomery, *An Introduction to Childhood: Anthropological Perspectives on Children's Lives* (Wiley-Blackwell 2009) 50.

<sup>6</sup> Jo Bridgeman and Daniel Monk ‘Introduction: Reflections on the Relationship between Feminism and Child Law’ in Jo Bridgeman and Daniel Monk (eds) *Feminist Perspectives on Child Law* (Cavendish 2000) 2.

<sup>7</sup> Fiona Kelly, ‘Conceptualising the Child through an “Ethic of Care”’: Lessons for Family Law [2005] *International Journal of Law in Context* 375, 376.

<sup>8</sup> Chris Jenks, *Childhood* (2<sup>nd</sup> edn, Routledge 2005) 4.

<sup>9</sup> Jean-Jacques Rousseau, *Emile* (London, JM Dent & Sons 1911).

<sup>10</sup> Emilie Durkheim, ‘Childhood [1911]’ in WSF Pickering (ed) *Durkheim: Essays on Morals and Education* (London, Routledge 1979) 150.

<sup>11</sup> Jenks (n8); Allison James and Alan Prout (eds) *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood* (2<sup>nd</sup> edn, Falmer Press, Taylor & Francis 2005).

relationships should be valued for what they are here and now.<sup>12</sup> A corresponding interest in children's rights has provided a vehicle whereby children may assert or seek protection for their present interests.

This Chapter will begin by briefly outlining the legal definition of the child. Next I determine the salient features of mid-childhood and explore the extent to which the law recognises or accommodates these. A review of the ways in which the construction of the child within developmental psychology, neuroscience and sociology has influenced the legal construction of the child, will follow. The key legal themes of welfare or rights will then be explored by analysing the tensions between them and the integral concepts of parental responsibility, best interests and competence. The discussion will be drawn together by seeking to present an alternative to welfare or rights, which has its foundation within care – that of Bridgeman's 'relational responsibility'.<sup>13</sup> Here I will seek to interpret and expand upon Bridgeman's three 'normative guidelines' that were discussed in Chapter 1.<sup>14</sup> I propose six facets of a relational conceptualization of mid-childhood, which would shift the focus away solely from the '(...) responsibilities of parents and healthcare professionals for the management of children's health'<sup>15</sup> to also include the responsibility that children themselves might bear. Finally, I will argue such a conception would transform decision-making concerning children's healthcare by placing the child's relational identity at the centre of the process and fostering greater participation of the child themselves in decisions about their own health.

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<sup>12</sup> Nick Lee, *Childhood and Society: Growing Up in an Age of Uncertainty* (2001 OUP); Emma Uprichard, 'Children as "Beings and Becomings": Children, Childhood and Temporality' (2008) 22(4) *Children and Society* 303.

<sup>13</sup> Jo Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (CUP 2007) 228.

<sup>14</sup> Chapter 1.

<sup>15</sup> Bridgeman (n13) 1.

## **Section 1 – Defining the ‘Child’ and the Importance of Mid-**

### **Childhood**

#### **1.1- Legal Definition of the Child**

Within contemporary legal and political thought, most States define the ‘age of majority’ - the age at which a person is legally recognized as an adult, as 18.<sup>16</sup> This stance is confirmed by the United Nations Convention on the Rights of the Child 1989 (UNCRC), which in Art 1 states that a ‘a child means every human being below the age of 18 years, unless under the law applicable to that child, majority is attained earlier’.<sup>17</sup> Yet, drawing such a stark chronological line between childhood and adulthood is clearly arbitrary and appears to have its basis in political considerations. This is illustrated by noting that notwithstanding the age of majority, most states grant ‘licence’ for activities that are indicative of adulthood, but at ages other than that of majority. For instance, in England and Wales, a person can have sex or marry (with parental permission) at 16, drive a car at 17 but may not adopt children until they are 21. Neither the cut off point of childhood at the age of 18 nor the various ages of ‘licence’ seem to bear any relation to corresponding mental or physical maturity, rather they appear to be societally determined.<sup>18</sup> Regardless of precisely how the boundaries of childhood are drawn, certain features appear to be common; that the child is developmentally immature, that the child is vulnerable, dependent and in need of protection, and that this protection should primarily be provided by the parents, who exercise some measure of ‘control’ over the child.

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<sup>16</sup> The age of majority is 18 in the UK. See Family Law Reform Act 1969, s1 Children Act 1989, s105(1).

<sup>17</sup> This compromise position of the UNCRC reflects the notion that domestic law should be respected in states where the age of majority can be as lower. In Iran, for girls it may be as low as 9 years old. In Iraq and Indonesia (for girls) it is 15.

<sup>18</sup> Flekkoy (n4) 13.

## 1.2 - The Focus on Mid Childhood

Samantha Brennan notes that although we often view childhood merely as a stage between the extremes of infancy and mature adulthood, that many of the ‘interesting questions and issues arise with children whose abilities are in between.’<sup>19</sup> The focus of this thesis is to explore these interesting questions and issues by concentrating on children in the mid years of childhood. Child Development models define middle childhood as the period falling between the ages of 6-12 years old.<sup>20</sup> However, as one of the purposes of this thesis is to consider the potential for the child to participate in decision-making to a meaningful extent, I propose to focus on the latter end of this period, from approximately the age of 8 and to extend it to include early adolescence, up to the age of 15. This period is pertinent because there appears to be a gap in the academic literature on children’s healthcare and the law, much of which has focused either on the complete dependency of infants or severely disabled children, or the difficult questions surrounding the autonomy of the near-adult ‘mature minor’. Indeed, Jo Bridgeman’s model of relational responsibility is constructed for use when considering the healthcare needs of young and dependent children only.<sup>21</sup> I wish to explore mid childhood, firstly because of the interest which is apparent in the ‘messy but morally important (...)’<sup>22</sup> reality of children who are neither completely dependent nor fully autonomous (to the extent that any adult ever is). Rather they appear to exhibit a range of capabilities, understanding and experience and may be characterized as ‘(...) a paradoxical mix of real vulnerability and authentic

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<sup>19</sup> Samantha Brennan, ‘Children’s Choices or Children’s Interests: Which do their Rights Protect?’ in David Archard and Colin Macleod (eds), *The Moral and Political Status of Children* (OUP 2002) 65.

<sup>20</sup> Centers for Disease Control and Prevention, ‘Middle Childhood’

<[www.cdc.gov/ncbddd/childdevelopment/postiveparenting/middle.html](http://www.cdc.gov/ncbddd/childdevelopment/postiveparenting/middle.html)> < Accessed 20 October 2013>

<sup>21</sup> Bridgeman (n13) 42.

<sup>22</sup> *ibid* 65.



strength'.<sup>23</sup> Second, I wish to explore whether Bridgeman's model will survive expansion to cover the greater complexities which arise when children become active subjects within their own healthcare decision-making and the law attempts to juggle consideration of their '(...) needs and choices, protection and independence, strengths and weaknesses'.<sup>24</sup>

Notwithstanding the aforementioned diversity within mid-childhood, a recurring theme can be seen as one of 'change'. The focus is less on physical growth and more upon the developing social and emotional worlds.<sup>25</sup> Of particular importance are not only the cognitive and language development of mid-childhood, but also the social and emotional development that provides the experiences of relatedness that become 'the crucible in which the *self* is forged'.<sup>26</sup> Both how these developmental markers have been interpreted within various disciplines and how this has created the rationale for the presumptions that underlie the legal construction of the child will be explored in Section 2, below.

## **Section 2 - Influence upon the Law of Constructions of the 'Child'**

### **2.1 - Developmental Psychology**

Developmental psychology has remained a privileged source of knowledge in relation to contemporary legal conceptions of children and childhood.<sup>27</sup> Its basic premise is that the child begins as an irrational being that will gradually progress, in a linear,

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<sup>23</sup> Shauna Van Praagh, 'Adolescence, Autonomy and Harry Potter: The Child as Decision-Maker' [2005] *International Journal of Law in Context* 335.

<sup>24</sup> *ibid* 336.

<sup>25</sup> Anastasia de Waal, 'Why Middle Childhood is so Critical' <[www.civitas.org.uk/pubs/midchild](http://www.civitas.org.uk/pubs/midchild)> <Accessed 20 July 2013>

<sup>26</sup> Benjamin Garber, *Developmental Psychology For Family Law Professionals: Theory, Application and the Best Interests of the Child* (New York; Springer Publishing Company 2010) 69.

<sup>27</sup> Karen Smith, 'Producing Governable Subjects: Images of Childhood Old and New' (2011) 19(1) *Childhood* 24, 30.

age-based way through various stages within which she will gain an increase in social skills, moral capacity or powers of rationality as he moves towards full adult competence. This model views the stages as inevitable because they are natural, rather than socially constructed.

As discussed in Chapter 1,<sup>28</sup> theories of psychological development began in the 1920s with the cognitive models of Watson<sup>29</sup> and Piaget.<sup>30</sup> Later Freud presented a five-stage theory of psychosexual development<sup>31</sup> and Eric Erikson presented a child's development as a series of successive 'crisis' to be navigated on the journey to adulthood.<sup>32</sup> However, it was Lawrence Kohlberg's tripartite theory of moral development, with its highest stages deriving from an abstract understanding of human rights,<sup>33</sup> which gave rise to Gilligan's objections and ultimately the development of the Ethics of Care.<sup>34</sup> In one sense, developmental models are valuable per se for recognizing the developing capacities of children in a field that has largely ignored them. They have demonstrated the value that lies in childhood and its future implications for adult personality, which have subsequently formed the basis for both the welfare and rights approaches of modernity.<sup>35</sup>

However, whilst contemporary Developmental Psychology resists painting the child in mid-childhood or early adolescence in either a strictly structural or strictly

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<sup>28</sup> Chapter 1.

<sup>29</sup> John B Watson, *Psychological Care of Infant and Child* (1928).

<sup>30</sup> Jean Piaget, *The Moral Judgment of the Child* (1932).

<sup>31</sup> Sigmund Freud, *Three Essays of the Theory of Sexuality* (1905), *Beyond the Pleasure Principle* (1920), *The Ego and the Id* (1923).

<sup>32</sup> Eric Erikson, *Identity, Youth and Crisis* (1965 Norton).

<sup>33</sup> Lawrence Kohlberg, 'The Development of Modes of Thinking and Choices in Years 10-16' (1958 PhD Dissertation, University of Chicago).

<sup>34</sup> Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (2<sup>nd</sup> edn 1993, Harvard University Press 1993).

<sup>35</sup> Flekkoy (n4) 23.

functionalist light, it does still acknowledge broad stages of macro development.<sup>36</sup> In this sense Gilligan's objections continue to resonate. Developmentalism by its nature involves a process of 'grading children' as they progress through a predetermined sequence of stages, evaluating them against what James et al deem a 'gold standard'.<sup>37</sup> Such a process may carry with it significant repercussions for those children who deviate from that standard. Further, developmentalism's focus upon rational development 'gives scientific credibility to the idea that children are not yet something – they are in a state of transition to completion (...)',<sup>38</sup> thereby obscuring other morally relevant features of a child's present experience. Alderson and Montgomery are persuasive in claiming that these developmental studies have long been refuted as they produced 'evidence' which greatly underestimated children's capacities.<sup>39</sup>

Although, Piaget's idea's of successive stages have been largely discredited<sup>40</sup> and Erikson's 'crises' model has been much criticised,<sup>41</sup> it is undeniable that older children *do* display greater sophistication in their modes of rationality and moral reasoning than their younger counterparts.<sup>42</sup> Given the still pervasive nature of developmental theories and their continued influence upon law and policy, it is pragmatic to consider if developmentalism may be used, at least as one element, to advance the argument for a relational conceptualisation of the child. Although the Ethics of Care may object to formal, rigid categorization, the modern recognition of

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<sup>36</sup> Kurt W Fischer and Daniel Bullock, 'Cognitive Development in School-Age Children: Conclusions and New Directions' in W Andrew Collins (ed), *Development during Middle Childhood: The Years from Six to Twelve* (1984 National Academy Press) 71.

<sup>37</sup> Allison James, Chris Jenks and Alan Prout, *Theorizing Childhood* (Polity Press 1998) 19.

<sup>38</sup> Alison Diduck, *Law's Families* (LexisNexis Butterworths 2003) 76.

<sup>39</sup> Alderson (n1) 7.

<sup>40</sup> John Coleman and Leo Hendry, *The Nature of Adolescence* (Routledge 1999) 36-43.

<sup>41</sup> *ibid* 59-65.

<sup>42</sup> Michael Rutter and Marjorie Rutter, *Developing Minds: Challenge and Continuity across the Life Span* (Penguin 1993) 195-197.

‘developmental unevenness’ where developmental sequences are viewed as relative, ‘(...) changing with the child, the immediate situation and the culture’,<sup>43</sup> is more in keeping with the particularist nature of care. Further the *content* of the categories identified in almost all models for those in mid childhood, appear entirely compatible with an Ethics of Care approach. For example, Piaget’s model places children aged 7-11 in the ‘concrete operational stage’ characterised by a move away from egocentrism towards logical but concrete reasoning; exactly the kind of bottom-up practical stance which is required by the Ethics of Care. Likewise, both Freud’s model which viewed mid-childhood as a period of sexual latency, where gratification was found in the sociality of school and the formation of relationships with peers<sup>44</sup> and Kohlberg’s, discussed above, illustrate the vital importance of the close relationships and sociality at this point in a child’s life. Only, in Eric Erikson’s theory of psychosocial development is there an indication that questions of identity must precede those of intimacy.<sup>45</sup> He places children from the ages of 6-12 at the 4<sup>th</sup> stage, marked by the crisis of ‘Industry versus Inferiority’,<sup>46</sup> where the child ‘strives to learn and master the technology of their culture, in order to recognize themselves and to be recognized by others (...)’ - here the focus is on the development of the individual self, in competition not cooperation. In all other models, relationality, if not the ultimate end goal, is acknowledged as key in mid-childhood. Likewise, associated themes such as striving for emotional balance, achieving a degree of impulse control, beginning to form empathy and cultivating an understanding of personal responsibility,<sup>47</sup> resonate strongly with an Ethics of Care. Indeed Shauna Van Praagh argues that early adolescence (and I would include late childhood) is characterized

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<sup>43</sup> Fischer (n36) 76.

<sup>44</sup> Freud (n31).

<sup>45</sup> Gilligan (n34) 12.

<sup>46</sup> Erikson (n32).

<sup>47</sup> Garber (n26) 84-88.

precisely as a ‘(...) time of transition, a time in which webs of significant people are created, a time of recasting relationships with family, institutions, peers and teachers (...)’<sup>48</sup> and I would argue a time in which the Ethics of Care may be commended as ideal model in which to capture these relational complexities.

## 2.2 - Neuroscience

More recent discoveries in the field of neuroscience, have shed new light upon children’s capabilities. In one respect neuroscience has demonstrated that children and adolescents are less developed than previously thought, with the prefrontal regions of the brain, which are important for tasks such as planning ahead, anticipating the future consequences of decisions, controlling impulses and comparing risk and reward, not fully mature until the mid 20’s.<sup>49</sup> However, neuroscience *does* demonstrate that the areas of the brain responsible for logical reasoning are mature from about the age of 14.<sup>50</sup> Daniel Slotnik has observed that ‘[t]his is why 16-year olds are just as competent as adults when it comes to granting informed medical consent, but still immature in ways that diminish their criminal responsibility (...)’.<sup>51</sup> Yet to date, the law bears no relation to these scientific truths and often runs counter to them. Criminal responsibility is acquired at just age 10,<sup>52</sup> when neuroscience suggests it should be much later. In contrast, the legal presumption that those aged 16 or above

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<sup>48</sup> Van Praagh (n23) 339.

<sup>49</sup> Daniel E Slotnick, ‘When do you become an Adult?’ (30 May 2012) New York Times – Education <[learning.blogs.nytimes.com/2012/05/30/when-do-you-become-an-adult/?\\_r=0](http://learning.blogs.nytimes.com/2012/05/30/when-do-you-become-an-adult/?_r=0)> <Accessed 29 July 2013>

<sup>50</sup> Michael Rutter (Chairman) *Commission on Families and the Wellbeing of Children, Families and the State: Two-Way Support and Responsibilities* (The Policy Press 2005) 33.

<sup>51</sup> *ibid*

<sup>52</sup> Children and Young Persons Act 1935, s50 and the abolition of the rebuttable presumption of *doli incapax* in Crime and Disorder Act 1998, s34.

have the capacity to consent to medical treatment,<sup>53</sup> has often been rebutted by the courts, under a protectionist agenda.<sup>54</sup>

### 2.3 - Sociology – “Becoming” v “Being”

Despite the scientific legitimacy of the development of rationality as demonstrated by developmental psychology and neuroscience, for the Ethics of Care there are other morally relevant considerations, including a child’s socialization and personal experience.

#### 2.3.1 - The ‘Dionysian’ or ‘Apollonian’ Child and the socialization model.

Alison Diduck observes that the conceptualisation of childhood as a ‘condition’ has its roots in Enlightenment thinking, where the move towards rational individualism excluded children, who were deemed to be ‘incomplete adults’<sup>55</sup> or ‘citizens in waiting’.<sup>56</sup> Even if children displayed competencies in certain areas, such as mastering a skill needed for employment, they were still regarded as ‘lacking a full component of adulthood’.<sup>57</sup> Childhood, so conceived, essentially portrays childhood as a state of ‘becoming and not being’. Arneil discusses the state of ‘becoming’ with the potential to be examined in three aspects. The first is the ‘end product’ of becoming – that defined by John Locke as liberal citizenship, marked by emerging rationality.<sup>58</sup> The second is the process of becoming via education, which acts as the main focus of parental responsibility.<sup>59</sup> The third is that the scope of becoming, with its focus upon

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<sup>53</sup> Family Law Reform Act s8 (1).

<sup>54</sup> See the Discussion in Chapter 3.

<sup>55</sup> Diduck (n38) 75.

<sup>56</sup> Barbara Arneil, ‘Becoming versus Being: A Critical Analysis of the Child in Liberal Theory’ in David Archard and Colin Macleod, *The Moral and Political Status of Children* (OUP 2002) 70.

<sup>57</sup> Montgomery (n5) 56.

<sup>58</sup> John Locke, *The Two Treatises of Government* (CUP 1989).

<sup>59</sup> Arneil (n56) 73.

rationality and education, is limited to children of school age. Therefore infants who are pre-rational are viewed as ‘pre-becomings’.<sup>60</sup>

Chris Jenks presents two competing conceptualisations of the child as a ‘becoming’.<sup>61</sup>

The first is inhabited by the ‘Dionysian’ or evil child, who is characterized by his ‘wildness, willfulness and sensuality (...)’.<sup>62</sup> This is contrasted with the ‘Apollonian’ or innocent child. I concur with Karen Smith’s view that this has become the paradigmatic, modern, western conception of childhood, where the child is seen as intrinsically good, ‘even angelic’.<sup>63</sup> However, Jonathan Herring rightly observes that the media and the law often straddle the divide between these two conceptualisations of children and childhood.<sup>64</sup> He identifies the tensions in a construction that, on one hand seeks to protect children from the sexualisation and commercialization which would rob them of their *innocence*, and on the other, the growing exclusion of children from public spaces because their *antisocial* or unruly behavior precludes them from participation. He notes that ‘(...) children are simultaneously being treated as dangerous young people in need of control in some areas of life, but also as vulnerable minors needing protection and/or restraint. Are they little angels or little devils?’<sup>65</sup>

Under either view the child becomes an ongoing project to be transformed. In the former case it is through a process of strict control, discipline and conformity to social

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<sup>60</sup> *ibid* 74.

<sup>61</sup> Jenks (n8).

<sup>62</sup> Smith, (n27) 25.

<sup>63</sup> *ibid* 26.

<sup>64</sup> See for example, Daily Mail, ‘They really are growing up fast: Pressures of modern world are eroding childhood’ *Daily Mail* (24 September 2011); Tim Lott, ‘What exactly is the Innocence of Childhood’ *The Guardian* (10 May 2013); Rebecca Camber, ‘Truth about Britain’s Feral Youth’ *Daily Mail* (24 June 2012).

<sup>65</sup> Herring (n2) 398.

norms, in order to produce a fully social and autonomous adult.<sup>66</sup> In the latter, via a process that is more child-centred, but is nonetheless a form of protectionist control. Smith argues that both conceptualisations share a common goal – that of the fostering of innocence, whether that be innate in the form of the Apollonian child or acquired in the case of the Dionysian.<sup>67</sup> Each would be achieved in law under a ‘welfare’ model. In each case, this happens through a process of ‘internalising conformity’ (one more subtle than the other) and absorbing norms and expectations from society, school and religious institutions, but primarily the family. This process appears to be akin to one of the three goals of ‘Maternal Practice’ identified by Ruddick- that of ‘training’ to become acceptable to the social world.<sup>68</sup>

Noggle considers the justification for parental power under the welfare model and concludes that in the case of young children it can be characterised as one of agency in a fiduciary type relationship due to the child’s ‘global cognitive defects’. However, he acknowledges that in adolescent children ‘parental authority seems to outlast the global cognitive deficits that characterize infancy and early childhood’.<sup>69</sup> Instead he attributes enduring parental power to children’s lesser ‘moral agency’, which he claims arises because they have not yet ‘fully developed an evaluative compass and internalized the moral norms necessary for the harmonious interaction with other

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<sup>66</sup> Arneil (n56)78.

<sup>67</sup> Smith (n27) 27.

<sup>68</sup> Sara Ruddick, *Maternal Thinking: Towards a Politics of Peace* (Beacon Press, Boston 1989) 113.

<sup>69</sup> Robert Noggle, ‘Special Agents: Children’s Autonomy and Parental Authority’ in David Archard and Colin Macleod, *The Moral and Political Status of Children* (OUP 2002) 99.



moral agents'.<sup>70</sup> However on another view this can be seen as the desire to maintain parental control and a pervading paternalism that claims that 'adults know best'.<sup>71</sup>

The focus of this model on first sight appears to have more in common with an Ethics of Care approach, in that the site for the socialization process is the family and that the necessary experience gained is in the context of relationships. However, upon closer inspection there is nothing of the child as a unique individual in their present concrete circumstances. Rather it appears to rely upon a property model, albeit one where the child's prime worth lies in his future self. Indeed, Diduck notes that 'all socialization theories tend to treat children as passive mounds of clay to be shaped, stretched or compressed into finished socialized products, and thus are more about what adults do to children than about how children experience their social space (...)'.<sup>72</sup>

Further, Archard and Macleod flag up the problem with viewing children as 'becomings', as one of categorizing them by what they are *not* rather than what they are. Arneil perceives that by viewing children merely as becomings, liberal theory has failed to view the world from the perspective of the child. By so doing it paints a false picture of children as being vulnerable, weak, and ignorant, and of adults as being self-sufficient, strong, and knowledgeable.<sup>73</sup> This false picture then forms the basis for the exclusion of children as full 'beings' '(...) exactly because they do not

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<sup>70</sup> *ibid* 100.

<sup>71</sup> Sara Fovargue and Suzanne Ost, 'Does the Theoretical Framework change the Legal End-Result for Mature Minors refusing Medical Treatment or Creating Self-Generated Pornography?' (2013) 13(1) *Medical Law International* 6, 8.

<sup>72</sup> Diduck (n38) 78.iufg

<sup>73</sup> David Archard and Colin Macleod, 'Introduction' in David Archard and Colin Macleod (eds) *The Moral and Political Status of Children* (OUP 2002) 2.

have the entrance requirements necessary to belong to the political sphere'.<sup>74</sup> My construction of the Ethics of Care would reject the 'becomings' thesis as being far too monolithic. Whilst acknowledging that children may have special vulnerabilities, due to their 'immaturity' it nonetheless would claim that each child should be viewed in the particularity of their own development, circumstances and experience. Indeed, as Alderson and Montgomery note '(...) the supposed chasm between foolish child and wise adult is a myth'.<sup>75</sup> Some children are strong, intelligent, wise and experienced, whilst some adults are foolish and dangerous.<sup>76</sup>

### 2.3.2 - The Late-Modern view – the Child as 'Being'.

Essential to the 'New Sociology' of childhood is the view of the child as a 'being' in and of himself, not merely for what he may become.<sup>77</sup> A study by Jane McCarthy demonstrates that rather than regarding their children as either willful or innocent, some mothers saw their children as 'little people'.<sup>78</sup> From this stance, childhood is viewed not in the abstract as natural or universal. Rather in the concrete from the actual child's perspective, albeit 'constrained by size, maturity and adult behaviour'.<sup>79</sup> Such a thesis would sit well within a care construction of the child, as it pays attention to the present reality of the child and thereby enables the consideration of undervalued traits and insights that children possess but may lose in the process of growing to adulthood.

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<sup>74</sup> Arneil (n56) 74.

<sup>75</sup> Alderson (n1) 5.

<sup>76</sup> *ibid*

<sup>77</sup> Jenks (n8).

<sup>78</sup> Jane Ribbens McCarthy, *Mothers and their Children: A Feminist Sociology of Childrearing* (Sage 1994).

<sup>79</sup> Montgomery (n5) 61.

James Dwyer's empirical work comparing children in mid childhood (ages 6-12) with middle-aged adults (40s and 50s) takes a multi-criteria and multi-degree approach and identifies triggers of moral intuition such as sympathetic identification, rational extension of self-estimation and awe – aspects of what he denotes as 'youthfulness'.<sup>80</sup> He discovered that the children came out ahead in almost the entire criterion, except for aspects of cognitive functioning.<sup>81</sup> Although, I would discount his conclusion that these characteristics of 'youthfulness' act as triggers of moral intuition that thereby grant children *superior* moral status as compared to adults,<sup>82</sup> his observations are valuable in flagging up that adult cognitive superiority does not outweigh all the other considerations that favour children.<sup>83</sup> Indeed Dwyer concludes that far from the purpose of childhood being to turn children into 'adults' that 'adults should seek to preserve their moral status by emulating children, by holding on to their youthfulness or childlikeness'.<sup>84</sup>

Diduck outlines the impact of viewing the child as 'being'. First, that development is seen as non-deterministic and life-long, not linear and finite. This sits comfortably with late-modern views of autonomy as interdependent and therefore that *all* human beings are to some extent both 'beings and 'becomings'. Second, it recognises the value of children's agency in affecting their environment, attachments and identity. While it is still necessary to acknowledge that children are dependent in ways and to degrees that many adults are not and subject to mechanisms of control that they are not, this new sociology reveals that children are indeed 'a component of all societies

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<sup>80</sup> James Dwyer, *Moral Status and Human Life: The Case for Children's Superiority* (CUP 2010).

<sup>81</sup> *ibid*

<sup>82</sup> *ibid* Chapter 3.

<sup>83</sup> *ibid* Chapter 5.

<sup>84</sup> *ibid*

and social structures (...)'.<sup>85</sup> Third, it gives value and respect to children's agency rather than assuming they are irrational or incompetent.<sup>86</sup>

## **Section 3 – Key Themes in the Legal Construction of the Child in Healthcare Law.**

### **3.1 - Legal Constructions – Property or Rights?**

#### **3.1.1 - The Child as Property**

Perhaps the oldest legal conceptualisation of the (legitimate) child is as the absolute property of his father.<sup>87</sup> This took the form of seeing the child as an 'economic investment'<sup>88</sup> as they became a necessary contributor to the family economy, or as an insurance policy for care of their parents in old age.<sup>89</sup> Another proprietary construction of the child is as 'an object of desire'<sup>90</sup> - a means of giving status to adults as they become parents, and to relationships as they shift from becoming partnerships or marriages to becoming 'families'.<sup>91</sup> In modern Western thought, conceiving of the child as property would sit ill at ease with contemporary family life and current developments within human rights. Archard and Macleod temper the stark propriety view by reconceiving the child as '(...) if not precisely a thing to be owned, none the less, (...) in some sense, an extension of the parent'.<sup>92</sup> This is a common view in societies such as Japan, where identity is defined very much on the basis of relationships and where the notion of the autonomous and individual self, especially

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<sup>85</sup> Diduck (n38) 81.

<sup>86</sup> *ibid* 83.

<sup>87</sup> Michael Freeman, 'Feminism and Child Law' in Jo Bridgeman and Daniel Monk (eds), *Feminist Perspectives on Child Law* (Cavendish 2000) 27.

<sup>88</sup> Montgomery (n5) 67.

<sup>89</sup> Flekkoy (n4) 12.

<sup>90</sup> Katherine O'Donovan, *Family Law Matters* (Pluto Press 1993) 93.

<sup>91</sup> Montgomery (n5) 64.

<sup>92</sup> Archard (n73) 1.

in relation to the child, is absent.<sup>93</sup> Yet the expression ‘my child’ can have proprietary as well as relational overtones and protestations that ‘children are not the property of their parents’ underlie the sense that in some ways children continue to be such.<sup>94</sup>

Katherine O’Donovan notes that much of Family Law still conceives of the child as an object and that ‘[t]here is a space in legal discourse, an emptiness, where a child’s individuality should be’.<sup>95</sup>

Justifications for a proprietary claim may trace their origins back to the ‘natural fact of generation,’<sup>96</sup> or that children are the products of their parents’ reproductive labour. However this ‘product’ O’Donovan argues, is placed beyond the market, creating the ‘instatement of children as household gods in child-centred families’.<sup>97</sup> Into the void steps family and healthcare law, wherein children may serve as an arena for parental power struggles or are the site for the operation of various professional groups, such as teachers, social workers and doctors, in each case residing in a space that enables children to be converted into legal objects.<sup>98</sup> Further, a paternalistic stance in the form of the welfare model may be adopted in recognition of the vulnerability and dependence of children and their inability to make good choices.<sup>99</sup> At its most extreme a proprietary view may be doing little more than endorsing the parental desire for power and control, which allows parents to ‘undermine their children’s self-confidence and capacity for self-determination’.<sup>100</sup> The Ethics of Care recognises the natural asymmetry that exists in relationships between parents and children because of

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<sup>93</sup> Montgomery (n5) 60.

<sup>94</sup> Barry Lyons, ‘“The Good that is Interred in their Bones”: Are there Property Rights in the Child?’ (2011) 19 Medical Law Review 373.

<sup>95</sup> O’Donovan (n90) 90.

<sup>96</sup> Archard (n73) 2.

<sup>97</sup> O’Donovan (n90) 93.

<sup>98</sup> *ibid* 91.

<sup>99</sup> Michael Freeman, *The Rights and Wrongs of Children* (Frances Pinter 1983) 53.

<sup>100</sup> Jane Fortin, *Children’s Rights and the Developing Law* (CUP 2009) 8.

the greater dependence of the child due to their relative lack of experience of life and the world. As such it would endorse, to some extent, welfarism in the name of responsibility. Nonetheless, the prime importance of caring relationships where ideally each would be engrossed in the views and situation of the other and motivated to act in accordance with them, would preclude any notion of the child as unspeaking property of the parents.

### 3.1.2 - Children's Rights

The law's increased interest in and sympathy for the notion of children as rights bearers, doubtless may be due to an overall increase in the level of 'rights consciousness',<sup>101</sup> perhaps combined with a greater willingness to view the child as a 'being' in her own right. Of course, children possess *human rights* simply by virtue of being human and the freedoms and protections encased within the European Convention of Human Rights (ECHR) and incorporated into the law of England and Wales by the Human Rights Act 1998 (HRA), are applicable to all. Undoubtedly, the United Nations Convention on the Rights of the Child 1989 (UNCRC) has been influential. Nonetheless Jane Fortin notes that these international instruments had a relatively late impact on the development of thinking around children's rights.<sup>102</sup> Rather, this arose from the concerns first expressed in the 1970s<sup>103</sup> around both the proprietary model of childhood and the predominance of developmentalism. Indeed Alderson has claimed that the UNCRC is the 'emancipation of children from the developmental theory'.<sup>104</sup>

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<sup>101</sup> *ibid* 3.

<sup>102</sup> *ibid*.

<sup>103</sup> Archard (n73) 3.

<sup>104</sup> Priscilla Alderson, 'Children's Rights and Michael Freeman' Conference Paper (1 July 2013) Current Legal Issues Colloquium, "Law and Michael Freeman" (UCL- Faculty of Laws, London).

Instrumental in this early movement were the approaches of Michael Freeman<sup>105</sup> and John Eekelaar.<sup>106</sup> For Freeman rights are vital to ensure that every child has their basic and fundamental interests considered. In an argument similar to that used to justify the welfare model, rights can be used as a powerful protection from inequalities and domination that may result when children's interests are taken advantage of, or seen as insignificant by, those in a position of greater power. He is alert to the danger that parental autonomy may be prioritized and that 'there is a tendency for the child's best interests to be over-identified with the parent's interests'.<sup>107</sup> However, he acknowledges the interest that parents do have in their child's safety and well-being and so advocates a position of 'liberal paternalism', whereby parental intervention is justified in situations where the decision made by the child would threaten serious harm to her.<sup>108</sup> Eekelaar presents a trifold account of children's *interests* - basic, developmental and autonomous, as the basis for possessing the corresponding right.<sup>109</sup> He identifies these by making a 'hypothetical retrospective judgment' to identify the kinds of benefits the child might have wanted looking back from once they have reached adulthood.<sup>110</sup> He ranks basic interests – those who attend to the child's physical, emotional and intellectual care, above developmental- where the child reaches out to the wider world in order to maximize his potential, which in turn take preference over autonomy rights, which cater to the need for self-determination and participation. Herring notes that Eekelaar's model 'has the benefit of providing an explanation of why children do not have all the rights of adults (...) and provides a

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<sup>105</sup> Freeman (n99).

<sup>106</sup> John Eekelaar, 'The Emergence of Children's Rights' (1986) 6 Oxford Journal of Legal Studies 161.

<sup>107</sup> Freeman (n87).

<sup>108</sup> Freeman (n99) 57.

<sup>109</sup> Eekelaar (n106).

<sup>110</sup> *ibid* 170.

sensible practical model enabling children to make some decisions for themselves, but not so as to cause themselves serious harm'.<sup>111</sup>

In terms of the content of children's rights, the UNCRC provides the benchmark. As the most ratified human rights treaty in the world,<sup>112</sup> it acknowledges that 'childhood is entitled to special care and assistance'<sup>113</sup> and compels States to respect and ensure the rights of each child free from discrimination.<sup>114</sup> Under the UNCRC children's rights fall into one of three categories- rights of protection, of development and of participation. Most pertinent to children's healthcare and decision-making is Article 12, which provides the child capable of forming his own views with the right to express them freely, and for them to be given due weight in accordance with the age and maturity of that child. Additionally, Article 13 provides the right to freedom of expression, including the freedom to seek, impart and receive information and ideas and Article 24, grants the right to the attainment of the highest standard of health and facilitates for treatment.

Whether children have rights at all is a source of intense debate. For those that subscribe to the 'will' or 'choice' theory of rights,<sup>115</sup> most children are precluded from being rights-bearers because they are unable to make a choice over the exercise of that right. Whereas those that adopt an 'interests' approach<sup>116</sup> allow for children's rights to be realized initially in the protection of their interests by others. This

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<sup>111</sup> Herring (n2) 437.

<sup>112</sup> Department for Education, 'Children and Young People' <[www.education.gov.uk/childrenandyoungpeople/healthandwellbeing.b0074766/uncrc](http://www.education.gov.uk/childrenandyoungpeople/healthandwellbeing.b0074766/uncrc)> Accessed 22 August 2013.

<sup>113</sup> UNCRC Preamble.

<sup>114</sup> UNCRD Art 2(1).

<sup>115</sup> See HLA Hart, 'Are there any Natural Rights?' in J Waldron (ed) *Theories of Rights* (OUP 1984) and Joel Feinberg, *Rights, Justice and the Bounds of Liberty* (Princeton University Press 1980).

<sup>116</sup> See Joseph Raz, *The Morality of Freedom* (Clarendon Press 1986) and Neil MacCormick, *Legal Right and Social Democracy: Essays in legal and Political Philosophy* (Clarendon Press 1982).



approach may be problematic in that young children are powerless to enforce their rights and are reliant upon the adults that may be breaching those rights.<sup>117</sup> Whilst this may be true for younger children, Fortin argues however that for older children, the interest theory can accommodate the notion of children acquiring freedom as they grow in capacity – ‘[i]n other words, children have an interest *in* choice, as they develop an ability to reach choices’.<sup>118</sup>

Some feminists argue that rights are not the answer. Elizabeth Kiss states that ‘[c]ultural feminists and feminist communitarians criticize rights for being overly abstract and impersonal and for reflecting and endorsing a selfish and atomistic vision of human nature and an excessively conflictual view of social life’.<sup>119</sup> Such objections may be even more powerful in the case of children, who are by necessity in relationships of dependency. As Jennifer Nedelsky observes that ‘(...) one of the reasons women have always fit so poorly into the framework of liberal theory is that it becomes obviously awkward to think of women’s relation to their children as essentially one of competing interests to be mediated by rights’.<sup>120</sup> So with children, as in the majority of cases, they would have neither the power nor the desire to assert their rights against those whom they are most interconnected with and reliant upon for financial, emotional and social support.

Further, just as welfarism can be criticised as being too ‘present-focused’, so rights tend to focus on the particular singular issue at that moment in time, isolating each

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<sup>117</sup> Fortin (n100) 13.

<sup>118</sup> *ibid* 14.

<sup>119</sup> Elizabeth Kiss, ‘Alchemy or Fool’s Gold? Assessing Feminist Doubts about Rights’ in M Lyndon Shanley and U Narayan (eds) *Reconstructing Political Theory: Feminist Perspectives* (Pennsylvania State University Press 1997) 2.

<sup>120</sup> Jennifer Nedelsky, ‘Reconceiving Rights and Constitutionalism’ (2008) 7(2) *Journal of Human Rights* 139, 145.

party in a very individualistic way. Tom Cockburn presents the concern that rights take us into the realm of the abstract and by so doing lose much of the subtlety of concrete reality when rights-based theories ‘attempt to sanitize abstract rules from the complexity of context’.<sup>121</sup> Likewise, Herring points out the flaws in Eekelaar’s approach in that by not allowing the child to make decisions in childhood which may limit future options in adulthood, that child may not be able to develop his skills sufficiently (for example in sport, art or music) in order to become the professional in adulthood that he may wish to be. This reasoning may also apply to religious commitments, whereby choosing to keep the child’s religious affiliation open may result in him being alienated from his religious community and unable to make that commitment in adulthood or create confusion in the child’s present by postponing the decision on a particular issue until some future time. Further the possibility that present choices may limit future ones, is relevant all throughout life, such as in performance at university, choices to undergo medical procedures etc, so it is unclear why such restrictions are justified only in children.<sup>122</sup>

### 3.2 - Parental Responsibility, the ‘Best Interests’ Test and Competence.

The Law’s current construction of the child owes much to each of the models discussed above. Developmentalism, in particular has had a tremendous impact on the law.<sup>123</sup> Diduck offers a traditional paradigm of childhood by pulling together a number of the models into a view she calls ‘romantic developmentalism’.<sup>124</sup> This is an Enlightenment construction based on a child’s position within the romantic family that integrates the innocent child, the evil child and the child as a blank slate, along

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<sup>121</sup> Tom Cockburn, ‘Children and the Feminist Ethic of Care’ (2005) 12(1) *Childhood* 71, 77.

<sup>122</sup> Herring (n2) 438.

<sup>123</sup> Diduck (n38) 76.

<sup>124</sup> *ibid* 79.

with certain 'truths' from developmental psychology and socialization. The composition of the child under this paradigm is one who is dependent, innocent (in both absolute moral terms, and of worldly matters such as citizenship, production and consumption), needing to grow to mature independence, 'being taught or guided (socialised) by loving carers attentive to their welfare so as to ensure that they do not reach this state prematurely and thus be corrupted'.<sup>125</sup> However, Diduck recognises the tension reflected in the law's reliance upon the developmental model by its dual aims to protect the child's welfare on one hand, whilst respecting their autonomy, independence and 'rights' on the other. Although romantic developmentalism still holds sway to a large extent, new conceptualisations of the child necessitate a concession '(...) at least that children have some part to play in constituting their worlds, including their identities and their relationships, and we are already radically reformulating traditional ideas of the romantic developmental child'.<sup>126</sup>

### 3.2.1 - Parental Responsibility

The influence of the romantic developmental model is evidenced in the law's concern for children's 'welfare' through its construction of parental responsibility. Only in the last 20 or so years has the concept of parental *responsibility* for children arisen, emphasizing that 'children should be beneficiaries of parenting rather than possessions of parents'.<sup>127</sup> This general concept and that of the 'best interests' test with its accompanying welfare checklist, became enshrined in law in the Children Act 1989.<sup>128</sup> Section 3 defines Parental Responsibility as

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<sup>125</sup> *ibid*

<sup>126</sup> Diduck (n38) 82.

<sup>127</sup> Michael Freeman, 'Whose Life is it Anyway?' (2001) 9 (3) *Medical Law Review* 259.

<sup>128</sup> s3.

‘all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property’.

Although this definition of parental responsibility is vague, Herring interprets it to mean the ability to make decisions about all areas of the child’s life subject to exceptions under the criminal law, the requirement to consult another with parental responsibility, the power of the local authority to take a child into care, a court order, or the wishes of a ‘*Gillick*-competent’ child.<sup>129</sup> O’Donovan argues that granting parental responsibility, in some respects, marks a retreat of the law from claims of knowledge of children’s best interests – leaving it to parents to know best and settle their children’s futures privately.<sup>130</sup> This may then link back to the propriety model of childhood, where parental responsibility facilitates the exercise of parental power over children. However, it is clear within responsibility parents do have parental rights but these are closely tied to the discharge of their responsibilities and some argue only subsist for as long as they are needed for the protection of the child.<sup>131</sup> Archard and Macleod have dubbed this ‘constrained parental paternalism’.<sup>132</sup> It is constrained both in that it can only be exercised for the *good* of the child, and that it will diminish as the capacity of the child grows. In some respects this ties in well with an Ethics of Care approach in which each party to the relationship has a responsibility for the other. But a care construction may differ in that the sense of responsibility, although dynamic is not finite, in that it endures throughout the relationship, whereas parental responsibility ceases once the child reaches 18.

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<sup>129</sup> Herring (n2) 407. See discussion below of the *Gillick* case in section 3.2.3.

<sup>130</sup> O’Donovan (n90) 95.

<sup>131</sup> *Gillick v W Norfolk and Wisbech AHA* [1986] AC 112, 184 [Lord Scarman].

<sup>132</sup> Archard (n73) 2.

### 3.2.2 - The Best Interests Test and the Welfare Checklist

The ‘welfare principle’<sup>133</sup> is the foundational principle of the Children Act 1989.

S1(1) states that whenever a court is to determine any question with respect to the upbringing of a child or the administration of a child’s property or application of any income arising from it, the child’s welfare shall be the court’s *paramount* consideration. The use of the word paramount has been interpreted as meaning that the child’s welfare must be the sole consideration.<sup>134</sup> This can be contrasted with the stance in the UNCRC, where best interests are still the ‘guiding principle’<sup>135</sup> but with the notable difference that they are to be the *primary* consideration.<sup>136</sup> This apparently leaves at least some scope for consideration of interests other than the child’s.<sup>137</sup> S1(3) CA 1989 supplies the ‘welfare checklist’ – a list of factors to aid the court in determining the child’s welfare (or best interests). The list is as follows:

- (a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding);
- (b) his physical, emotional and educational needs;
- (c) the likely effect on him of any change in his circumstances;
- (d) his age, sex, background and any characteristics of his which the court considers relevant;
- (e) any harm which he has suffered or is at risk of suffering;
- (f) how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs;
- (g) the range of powers available to the court under this Act in the proceedings in question.

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<sup>133</sup> The term ‘best interests’ is often used interchangeably with the term ‘welfare’.

<sup>134</sup> Herring (n2) 38.

<sup>135</sup> Flekkay (n4) 27.

<sup>136</sup> UNCRC Art 3.

<sup>137</sup> *ibid*

Although the application of the best interests test will be examined in much greater detail in Chapter 3,<sup>138</sup> it is pertinent here to examine the theoretical underpinnings to the test. It can be argued that the best interests model, by placing the child's welfare as the sole consideration, is a powerful tool to protect interests that might otherwise be easily overlooked or overruled by those in a more powerful position. It attempts to give a 'voice' to the child's perspective in situations where they might otherwise not be heard, such as within court.<sup>139</sup> Yet in reality, although the law does attempt to take account of the child's wishes and feelings, the child's views can be trumped by larger welfare considerations. Diduck notes that the weight given to those wishes depends upon adult constructions of the child's competency and level of understanding, and therefore means that they are more likely to be heard if they conform to adult ideas of welfare.<sup>140</sup>

However, the best interests approach has faced sustained criticism, as discussed in Chapter 3. By way of outline here, the essence of the objections lie in its vagueness<sup>141</sup> and the unpredictability of the weighing and application of its factors and their susceptibility to the bias and prejudice of the decision-maker who is interpreting them.<sup>142</sup> However, under a care orientation, Herring is correct to note that such objections are less problematic as the Ethics of Care tends to prize flexible, particularist approaches.<sup>143</sup> Rather, the prime objection is that the 'welfare checklist' makes no mention of the quality or strength of the child's relationships. Its aim is to

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<sup>138</sup> Chapter 3,

<sup>139</sup> Jonathan Herring, 'Farewell Welfare?' (2005) 27 *Journal of Social Welfare and Family Law* 159.

<sup>140</sup> Diduck (n38) 92.

<sup>141</sup> Sarah Elliston, *The Best Interests of the Child in Healthcare* (Routledge-Cavendish 2007) 17.

<sup>142</sup> David Archard, 'Children, Adults, Best Interests and Rights' (2013) 13(1) *Medical Law International* 55, 56.

<sup>143</sup> Herring (n2) 40.

‘maximize’ the child’s interests. In line with care thinking, Archard moves away from a strict construction and rejects the notion of ‘maximizing’ a child’s welfare as implausible. Rather he interprets the principle as one requiring the well-being of the child to be no more than a consideration and a constraint.<sup>144</sup> Indeed, Eekelaar argues that in order to protect “family life” as enshrined in Human Rights conventions, there needs to be some reform of the domestic law away from a sole focus on the child’s welfare to include a balancing of children’s welfare with adults and family interests, even if such rebalancing might result in less than optimal results for children.<sup>145</sup>

Archard and Macleod argue for a more complex portrayal of the welfare model, with the consequence that it is no longer possible to view the relationship between children and those who are responsible for them as necessarily harmonious.<sup>146</sup> Rather, it creates the imperative to look deeper to understand children’s interests and to ‘explore how the conceptualization of children’s interests affects the character of the moral claims they have’.<sup>147</sup> Although, this may be stretching the construction of the test in the CA further than the courts may be willing to take it, this kind of a construction would fit well with a ‘mature’ view of the Ethics of Care first presented by Gilligan<sup>148</sup> and developed by Tove Pettersen.<sup>149</sup> Firstly, it would allow the interests of self of the child and the others of those in caring relationships with him to be reconciled by being honest about the needs and wants of each party. There are clearly times when parents’ interests may outweigh those of a child.

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<sup>144</sup> Archard (n142) 56.

<sup>145</sup> John Eekelaar, ‘Children between Cultures’ (2004) 18 *International Journal of Law, Policy and the Family* 178, 186-7.

<sup>146</sup> Archard (n73) 4.

<sup>147</sup> *ibid*

<sup>148</sup> Gilligan (n34) 74.

<sup>149</sup> Tove Pettersen ‘The Ethics of Care: Normative Structures and Empirical Observations’ (2011) 19(1) *Health Care Analysis* 51.

As noted by Archard:

[a] parent has a legitimate interest in leading a certain kind of life that is not reducible to what is best for its child. It is also arguable- though contentious- that the parent has an interest in promoting the value of the family as such that may- subject to the guarantee of a child's essential interests – compromise the child's best interests.<sup>150</sup>

This takes an expansive relational view of best interests, which whilst accommodating the interconnected nature of family relationships and the impact that decisions have on all family members, also appreciates that such interconnection sometimes acts to obscure the individual needs of the adults in the relation, who are not solely defined by their parental status. Further it provides for a holistic balancing of the family's interests, which allows for certain compromises of the individual child's maximized best interests in order to satisfy a broader whole family vision of the good. Flekkoy goes further by suggesting that there may also be situations where the competing interests of justice or society should deserve at least equal consideration or even greater emphasis than the best interests of the child.<sup>151</sup>

Secondly, the welfare model under a care orientation could incorporate a scrutinising mechanism rather than automatically presume that all relationships are 'good'. As argued in Chapter 1, it is imperative to begin from a presumption of 'successful' caring relationships. If this scrutiny of the quality and longer-term impact of those

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<sup>150</sup> Archard (n142) 60.

<sup>151</sup> Flekkoy (n4) 45.



relationships reveals abuse, coercion or domination,<sup>152</sup> then Waldron's argument would suggest that rights may be employed as '(...) a fallback and security in case other constitutive elements of a social relationship ever come apart'.<sup>153</sup> Here, the most caring response will be to employ a justice orientation to bring to bear considerations of fairness, autonomy and equality.

### 3.2.3 - Child Competence

The developmental model has close ties with the concept of capacity, which is a central concept of healthcare law relating to children. Under the Family Law Reform Act 1969 it is presumed that those aged 16 or above have the capacity to consent to their own medical treatment, as if they were adults.<sup>154</sup> The Mental Capacity Act (MCA) 2005 sets out the test for mental capacity for adults.<sup>155</sup> Section 2 (1) states that a person lacks capacity if he is unable to make a decision for himself due to 'an impairment of, or disturbance in, the functioning of the mind, or brain'. Section 3(1) defines incapacity where a person is unable to:

- a) understand the information relevant to the decision
- b) retain that information
- c) use or weigh that information as part of the process of decision-making
- d) communicate his decision.

The implications of these two legislative provisions appear to be that once capacity is established the patient's rights of autonomy and self-determination come to the fore and the competent child must have his right to choose be protected. However, even

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<sup>152</sup> Herring (n2) 35.

<sup>153</sup> Jeremy Waldron, *Liberal Rights: Collected Papers 1891 – 1991* (CUP 1993) 374.

<sup>154</sup> S 8(1).

<sup>155</sup> See s2 and s3(1).

here a protectionist agenda is evident in the case-law, as discussed in Chapter 3,<sup>156</sup> where in instances of *refusal* of consent, the courts have shown a clear difference in treatment between children and adults.<sup>157</sup> Particularly in cases of life and death, the judge is likely to overrule the child's refusal of consent by drawing upon parental or the courts own consent, in the name of child's 'best interests'.<sup>158</sup> Indeed Fovargue and Ost claim that 'no case has been reported where a mature minor's refusal has been respected and that they have died, as a minor'.<sup>159</sup> It appears that those over 16 have the right to consent but only if they agree with medical, legal or parental opinion- a form of 'dependent compliance'.<sup>160</sup>

The legal presumption is reversed for children under 16, whose competence must be proven.<sup>161</sup> In the absence of legislative provisions, the common law prevails as found in the leading case of *Gillick v West Norfolk and Wisbech AHA*.<sup>162</sup> The case involved a challenge by Victoria Gillick to the legality of a memorandum of guidance issued by the Department of Health and Social Security to doctors. It stated that they might, in exceptional circumstances, provide contraceptive advice and treatment to girls aged under 16 without parental consent. Here the court held that such matters fell within the realm of medical ethics, rather than the law,<sup>163</sup> and ruled that if a doctor decides that the treatment is in the child's best interests and that she is competent to understand the issues, the treatment can be provided on the consent of the child alone. The judgment of Lord Scarman sums up the majority opinion, that:

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<sup>156</sup> Chapter 3,

<sup>157</sup> Adults may refuse medical treatment for reasons that are 'rational, irrational or for no reason at all' see *Sidaway v Board of Governors for Bethlem Royal Hospital* [1985] AC 871.

<sup>158</sup> *Re R (A Minor)(Wardship: Medical Treatment)* [1992] 4 All ER 177.

<sup>159</sup> Fovargue (n71) 12.

<sup>160</sup> Alderson (n3) 306.

<sup>161</sup> Elliston (n141) 77.

<sup>162</sup> [1985] 3 All ER 402.

<sup>163</sup> Jose Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart 2007) 89.

(...) the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when, the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed.<sup>164</sup>

In addition, Lord Scarman asserted that the child must also have ‘sufficient maturity’ to understand the moral, family, emotional and long-term health implications of her decision. Lord Fraser’s approach differed in that he set out a checklist of five factors (the Fraser Guidelines) for doctors to consider in determining whether the child has reached the level of competence required. These hinge on the child’s comprehension of the medical advice and require the proposed treatment is in her best interests. For those children who do not meet the threshold for competence, the best interests test continues to apply.

As I have written elsewhere,<sup>165</sup> whilst *Gillick* was hailed by Fortin as ‘remarkably enlightened’ in its recognition of the autonomy of children,<sup>166</sup> it has come under increasing strain.<sup>167</sup> There has been much disquiet over the theoretical coherence of *Gillick*.<sup>168</sup> As a decision that was made in the specific context of contraceptive advice and treatment, it has been applied to an ever-wider range of scenarios. In these subsequent cases however, as noted above, it became apparent that judges were

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<sup>164</sup> *ibid* 189.

<sup>165</sup> Kirsty Moreton, ‘Gillick Reinstated: Judging Mid-Childhood Competence in Healthcare Law: *An NHS Trust v ABC & A Local Authority* [2014] EWHC 1445 (fam)’ [2015] 23(2) *Medical Law Review* 303, 306.

<sup>166</sup> Fortin (n100) 8. 94.

<sup>167</sup> Emma Cave, ‘Goodbye *Gillick*? Identifying and resolving problems with the concept of child competence’ (2014) 34(1) *Legal Studies* 103,105.

<sup>168</sup> Stephen Gilmore and Jonathan Herring, “‘No’ is the Hardest Word: Consent and Children’s Autonomy’ (2011) 23 *Child & Family Law Quarterly* 3.

reluctant to allow even older adolescents to make determinative decisions.<sup>169</sup> Instead, judges either acknowledged the child's competence but overrode it in the name of best interests,<sup>170</sup> or manipulated the criteria for competence so that the bar was set so high that it was easy to find the child incompetent,<sup>171</sup> particularly so in relation to Lord Scarman's requirement that the child should understand the moral and social impact of her decision – something that we don't require for adults. Herring claims that the law, in drawing sharp distinctions between the capacity of adult and child, can be questioned by relational constructions.<sup>172</sup> He argues that it is unrealistic to claim that children below this threshold are vulnerable, whilst upon turning 18 (or attaining *Gillick* Competence) we all become mature, independent and capable. As I have written elsewhere,<sup>173</sup> relational models of decision-making consider that a person's competence is constructed within the web of relationships that surround them,<sup>174</sup> that relational influence and collaboration is a practical reality of decision-making<sup>175</sup> and that the impact of the decisions on those relationships is of ethical importance.<sup>176</sup>

The subsequent case of *R (On the Application of Axon) v Secretary of State for Health (Family Planning Association intervening)*,<sup>177</sup> gave the court the opportunity to examine how the principle of 'Gillick-competence' might relate to the HR protections to family life as provided by Art 8 ECHR and incorporated into domestic law under the HRA 1998. Whilst it purported to uphold *Gillick*, by confirming the end of

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<sup>169</sup> See Chapter 3 for a detailed discussion of these cases.

<sup>170</sup> See *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11; *Re W (A Minor) (Medical Treatment)* [1992] 4 All ER 627, [1993] Fam 64; *Re P (A Child)* [2014] EWHC 1650 (Fam).

<sup>171</sup> See *Re E (A Minor) (Wardship: Medical Treatment)* [1992] 2 FCR 219; *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810, [1999] 2 FCR 524.

<sup>172</sup> Herring (n2).

<sup>173</sup> Moreton (n165)304.

<sup>174</sup> Nedelsky (n120).

<sup>175</sup> David Archard, 'Children, Adults, Best Interests and Rights' (2013) 13(1) Medical Law International 55, 60.

<sup>176</sup> Herring (n2) 40.

<sup>177</sup> [2006] 1 FCR 175.

parental rights once the child attains competence, some commentators claimed that it in effect marked the legal retreat from *Gillick*.<sup>178</sup> This may be valid in the sense that as the case tightened the test by upholding the Fraser Guidelines whilst reading Lord Scarman's statements into them. It seems that either case has the effect, although possibly only in matters of sexual health, of requiring the child to show not only greater decision-making skills than the law requires of adults under the MCA 2005 but also that the decision is in the child's best interest.<sup>179</sup>

## **Section 4 – An Alternative Construction: The Ethics of Care and “Relational Responsibility”.**

### **4.1 - Viewing the child through the lens of ‘Relational Responsibility’ .**

Viewing the child and childhood through the lens of the Ethics of Care paints a picture that is both different to a rights or welfarist conception but also attempts to combine elements of both by valuing children's distinct status as individuals *and* their need for nurturance, love and discipline.<sup>180</sup> Sevenhuijsen has argued that the Ethics of Care can bring together rights and responsibilities within relationships, as care ‘is encapsulated in the idea that individuals can exist because they are members of various networks of care and responsibility, for good or bad’.<sup>181</sup> The current position within the law attempts to blend the best of the romantic developmental child and the child of late-modernity to create a ‘hybrid’ child – but only on law's terms. There *are* images of the independent, subjective child in certain areas of legal discourse, such as the decision in *Gillick*, the UNCRC and procedures for children to give evidence in

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<sup>178</sup> Gillian Douglas, ‘The Retreat from *Gillick*’ (1992) 55(4) Modern Law Review 569.

<sup>179</sup> Elliston (n141) 83.

<sup>180</sup> James Dwyer, *The Relationship Rights of Children* (CUP 2006) 15.

<sup>181</sup> Selma Sevenhuijsen, ‘An Approach through the Ethic of Care’ in A Carling, S Duncan and R Edwards (eds) *Analysing Families* (Routledge 2002) 131.

court, which show some commitment by the law to ‘create a child subject who bears some degree of legal and social subjectivity’.<sup>182</sup> However, I concur with Herring that adopting a full rights-based approach would require a ‘kind of complete rethinking of legal analysis and rewriting of legal terminology’ that is unlikely to happen in the near future.<sup>183</sup>

With this in mind I suggest the care orientation that I describe could be adopted within the welfare model and used as an interpretive tool of both ‘best interests’ and child competence. Herring has claimed that although the CA 1989 requires that the child’s welfare be the ‘paramount’ consideration, that the courts have sometimes found ways to consider or protect the interests of parents or carers at the same time.<sup>184</sup> Such a stance begins with the concept of responsibility within relationships. For Herring, within a relational approach we should begin from a presumption of obligation (a term he uses interchangeably with responsibility) rather than the typical liberal stance of freedom. He notes that the question should be not ‘is there a good reason to restrict my freedom’ but rather ‘is it possible to have some freedom, given the responsibilities of those I am connected to?’<sup>185</sup> He suggests that the child’s welfare is best represented through a relational model, in that their welfare is best protected when they are cared for in healthy relationships and decisions are made with the integrity of the family, as a whole, in mind.<sup>186</sup>

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<sup>182</sup> Diduck (n38) 94.

<sup>183</sup> Jonathan Herring, ‘Forging a Relational Approach: Best Interests or Human Rights?’ (2013) 13(1) *Medical Law International*, 32, 33.

<sup>184</sup> Herring (n139) 159

<sup>185</sup> Herring (n2) 37.

<sup>186</sup> Jonathan Herring, ‘The Human Rights Act and the Welfare Principle in Family Law: Conflicting or Complementary?’ (1999) 11 *Child and Family Law Quarterly* 223.

In fact, to take decisions in the absence of considering the child's relationships can be seen as counterproductive to prompting his welfare. As Dwyer notes, having moral obligations to care can encourage *both* parties to adopt a more other-centred approach.<sup>187</sup> This stance is justified on a pragmatic level because it represents the reality of the lives of most people, and on a theoretical one because it is within our relational responsibilities that human flourishing is realized.<sup>188</sup> Herring also argues that part of a fuller notion of welfare is to consider the value of doing something for others, even if it is not completely in our own interests, as part of an idea of what is required for maximum human flourishing. Lucinda Ferguson picks up on the connection between responsibility and human flourishing, by proposing a model that focuses on the virtue of the decision-maker rather than the rights of the child. Further, she suggests that a duty model could usefully be employed as an interpretative and resolutionary tool to resolve conflict and temper the parties wants in the event of an impasse.<sup>189</sup> So even if the decision that is made is not entirely in the child's best interests from a medical view point, it may still be good for his welfare, as part of the duties arising from the 'give-and-take' of living in relationships.

As noted in Chapter 1, the heart of the Ethics of Care is the moral value of relationships and the prime importance of relationality.<sup>190</sup> This commitment is reflected in Jo Bridgeman's three guidelines, which she claims should be met in an attitude of attentiveness, kindness and reciprocity.<sup>191</sup> A responsibilities approach would not mandate a particular action but rather offer a framework, a series of

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<sup>187</sup> Dwyer (n180) 13.

<sup>188</sup> *Ibid*

<sup>189</sup> Lucinda Ferguson, 'The Jurisprudence of Making Decisions Affecting Children: An Argument to Prefer Duty to Children's Rights and Welfare' in Alison Diduck, Noam Peleg, and Helen Reece, (eds) *Law and Michael Freeman* (Brill: Netherlands, 2014).

<sup>190</sup> Chapter 1.

<sup>191</sup> Bridgeman (n13) 228.

guidelines for deciding what to do in a given situation, informed by practices and understandings of responsibility'.<sup>192</sup> Bridgeman seeks to build a framework that avoids the traditional adversarial focus that pits parents and children against each other and the courts. Rather, she claims her model would dismantle current assumptions about the parent-child relationship,<sup>193</sup> by constructing a relationship that was not adversarial but mutually supportive.<sup>194</sup> I contend that applying the Ethics of Care alters our view of the child in six fundamental ways and that these facets of care may be used to illuminate and expand Bridgeman's model for use with children in mid-childhood. I argue that to adopt such a view would change the role of the State in relation to children, from one where it is only involved in issues relating to education or intervening in family breakdown or disagreement, to a more proactive, holistic function.<sup>195</sup>

#### 4.2 - Interpreting Relational Responsibility through the Ethics of Care

Here I will develop Bridgeman's framework and use it to measure judicial thinking as discussed in the Systematic Case Review in Chapter 3 and as a basis for the analysis in the case studies in Chapter 4-6. I believe that Bridgeman's tripartite framework is able to successfully accommodate the elements of self, others and relationship which are all necessary components of a theory of care. Although Bridgeman claims that her three normative guidelines need no further expansion because the content of them will depend on the particular circumstances of the child's healthcare needs,<sup>196</sup> as the model is being adapted for older children, it is pertinent to flag up how the Ethics of Care

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<sup>192</sup> Jo Bridgeman, 'Parental Responsibility, Responsible Parenting and Legal Regulation' in Jo Bridgeman, Heather Keating and Craig Lind (eds) *Responsibility, Law and the Family* (Ashgate 2008) 245.

<sup>193</sup> Bridgeman (n13) 44.

<sup>194</sup> Arneil (n56) 90.

<sup>195</sup> *ibid*

<sup>196</sup> Bridgeman (n13) 239.



conceives of children in mid-childhood. To this end I have identified six facets of a care construct of mid childhood; first, portrayal of the child as vulnerable; second, revealing the embodied nature of the child; third, placing the child in their concrete but changing reality; fourth, demonstrating the interconnected nature of the child, not only with parents but with siblings and friends; fifth, positing the child's experience as a source of expertise; and sixth, a consideration of the surrounding religious, cultural, social and political influences in a child's life and a need for scrutiny of the nature and quality of all the child's relationships. Each of these six facets will be incorporated into one of the three normative guidelines, within the discussion below.

#### 4.2.1 - Guideline One – Attentiveness to the Individual Interconnected Child in her Particular Circumstances

Bridgeman's Guideline One is 'attentiveness to the child as an individual with particular needs, wants and concerns',<sup>197</sup> and I have adapted this to become 'attentiveness to the individual interconnected child in her particular circumstances'.

It may appear here that Bridgeman is invoking a focus on the liberal individualism of autonomy, which would be at odds with the relationality of the Ethics of Care.

However, I interpret this guideline as requiring our first consideration to be the 'self' of the child in the *particularity* of his circumstances. This would require Noddings engrossment<sup>198</sup> on the part of decision-makers in order to discern the self of the child in three ways, as vulnerable, embodied and interconnected. Further, for an older child, there would be the potential for the child to be lifted him from being the object of care whose individual needs are determined by observation of parental opinion, to being

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<sup>197</sup> *ibid* 44.

<sup>198</sup> Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (University of California Press 1984).

self-determining, as there would have been greater time for the child to develop his individuality and greater scope for him to voice it.

First, the Ethics of Care portrays the child as vulnerable, something that it has in common with both 'best interests' and rights approaches. Yet care neither seeks necessarily to protect the child because of her vulnerabilities, nor empower her in spite of them, but rather recognizes that children are potentially vulnerable because we *all* inherently vulnerable,<sup>199</sup> by virtue of our physical humanity and emotional dependence upon one another. Although it is clear that children may have extra 'situational' vulnerabilities<sup>200</sup> such as inexperience of life or financial dependence, it is questionable how far decision-making frameworks should make special allowances for these.<sup>201</sup> Furthermore, in many ways these vulnerabilities are no less onerous than those faced by many adults and therefore do not, in and of themselves, justify treating children in a paternalistic fashion. The Ethics of Care facilitates a more comprehensive way to view children's vulnerabilities, which is not only through an inherent or situational lens but to consider it in the subjective sense through the child's own lived experience, by listening to the child's own 'voice'.<sup>202</sup>

Second, the Ethics of Care reveals the embodied reality of the child. By so doing, it brings the child's bodily experience to the forefront of decision-making. It enables a focus upon the pain, discomfort, distress or indeed pleasure felt by the child in relation to his healthcare condition as well as the bodily consequences of any

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<sup>199</sup> Hazel Biggs, *Healthcare Research Ethics and Law: Regulation, Review and Responsibility* (Routledge-Cavendish 2010) 160.

<sup>200</sup> Michael C Dunn, Isabel CH Clare and Anthony J Haland, 'To Empower or to Protect? Constructing the 'Vulnerable Adult' in English Law and Public Policy' (2008) 28(2) *Legal Studies* 235, 239.

<sup>201</sup> Alderson (n1) 4.

<sup>202</sup> Dunn (n200) 243.

proposed treatment or surgery. These bodily consequences must be weighed against any mental justification to consent to or refuse treatment, such as for altruistic motivations. Embodiment is especially pertinent to *children's* experiences, where they may lack the cognitive powers to articulate them but nonetheless understand them through their bodies. Further, conceiving of the child in an embodied state reflects the importance of body image as a means of identity. This may be particularly so, for children with a disability or for instance, for transgendered children. Embodiment may also reveal ways that older children communicate as they move through the physical world. This could range from violent resistance, to quiet withdrawal or a physical expression of relatedness to others which the child is unable to quite articulate but is able to express in bodily interaction, such as a child '(...) who cuddles the crying friend exhibits compassion and sympathy, even if they lack the mental capacity to express it in those terms'.<sup>203</sup> Finally the embodied child demonstrates a respect for his unique personhood and his right to bodily integrity, which is not so much a call for non-intervention, as being true to the self of the body and mind as the child sees it.

Third, the Ethics of Care shows us a childhood that is not necessarily a time of innocence or of untamed mischief but rather a concrete, yet constantly changing situation. Within this the present child has something to offer – not just as a future 'becoming', and so a care conceptualisation would have much in common with the 'being' thesis.<sup>204</sup> Here Dwyer's theory of youthfulness being linked to moral worth is confirmed in the thinking of Archard who observes that although some children might lack certain characteristics deemed to be paradigmatic of adulthood, conversely they

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<sup>203</sup> Herring (n2) 43.

<sup>204</sup> Arneil (n56) 88.

may also possess valuable characteristics that adults often lack – such as wonderment and innocence.<sup>205</sup> The key to childhood under the Ethics of Care is a particularist one, whereby the reality of the child may be ‘dependent and independent, rational and irrational at the very same time, to varying degrees, at different points in the day, as well as throughout their young lives’.<sup>206</sup> Clearly such a child neither follows along a subscribed linear developmental pathway, nor necessarily complies with the protocol of societal training.<sup>207</sup>

#### 4.2.2 - Guideline Two – Consideration of the Child’s Past and Future Caring

##### Relationships

Bridgeman’s Guideline Two is a ‘consideration of the history of caring practices focusing on the quality of the relationships and the expertise gained through actual caring’ by parents and healthcare professionals.<sup>208</sup> I shall deem it ‘consideration of the child’s past and future caring relationships’. This second step takes the Ethics of Care outside of the self of the child to view the value and quality of the caring relation and impact that it has had on others. By examining the impact of Nodding’s ‘Motivational Displacement’,<sup>209</sup> the actual care given by family and healthcare professionals can be assessed. Here the work of Ruddick, Held and Bowden,<sup>210</sup> demonstrate how the concrete practical experience of care can be used as a source of expertise, not only in the immediate moment of the decision-making but also to ascertain the longer term consequences for the caring relationship and those surrounding it.

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<sup>205</sup> Archard (n73) 13.

<sup>206</sup> Arneil (n56) 88.

<sup>207</sup> *ibid* 93.

<sup>208</sup> Bridgeman (n13) 44.

<sup>209</sup> Noddings (n198).

<sup>210</sup> Ruddick (n68); Virginia Held, *The Ethics of Care: Personal, Political and Global* (New York, OUP 2006); Peta Bowden, *Caring: Gender-Sensitive Ethics* (London, Routledge 1997).

Here the fourth facet demonstrates the crucial truth that the self of the child is not the individualistic, unconnected subject of much of best interests and rights-based decision-making but rather one firmly situated within relationships with family, friends or religious and cultural communities. Arneil argues that if the ‘unencumbered’ individual subject is difficult to sustain in theories about adults, it is even more so for children, who are especially interconnected, dependent and affected by society and culture. Indeed, she argues that relationality is even *more* vital for children than it is for adults, when she notes that ‘[e]xactly because children are dependent and growing beings, they can *only* be viewed as connected, in a constitutive sense, to their families and cultures’.<sup>211</sup> Such is the impact of this relationality that Herring is right to note that in many respects ‘[i]n relationships, the interests and well-being of the two people become merged’.<sup>212</sup> By way of recognition that children are aware of the importance of their relationships, we may go back to Gilligan’s original studies<sup>213</sup>, which are key because, whilst it is often overlooked in the male/female debate, she firstly engages with *children* from as young as 6 years old. These studies clearly demonstrate how many children think in relational terms when tasked with solving moral problems.

The fifth facet shows that this recognition of life within an embodied and relational state opens up the potential for the child to be a possessor of knowledge, gained from practical experience of care. By extending Sara Ruddick’s notion of ‘Maternal Thinking’<sup>214</sup> to the child’s experience, it can be argued that the child gains particular expertise and intimate knowledge by caring for themselves and understanding their

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<sup>211</sup> Arneil (56) 83.

<sup>212</sup> Herring (n2) 35.

<sup>213</sup> Gilligan (n34).

<sup>214</sup> Ruddick (n68).

own health condition in a way that no ‘impartial’ health professional or judge may be able to do. Further because the child is a participant in and not merely the object of, caring relationships, the child may be simultaneously the ‘cared-for’ and the ‘one-caring’.<sup>215</sup> An acknowledgement of children’s active role in relationships is a useful tool in challenging the paternalism that is often equated with care.<sup>216</sup> Alderson and Montgomery discount the view of children as necessarily ‘dependent long after infancy’ as a recent Western phenomenon and claim that ‘[a]fter infancy dependence is largely a matter of economics, social customs and beliefs’.<sup>217</sup> Even young children can be independent in adult ways, such as taking on employment from a young age, or by being carers to sick or disabled relatives.

Although the modern western construction of childhood is seen as a realm of fun, play and lack of responsibility, it is evident that children do acquire responsibilities (to a greater or lesser degree) by virtue of their relational state. These may be responsibilities to others with whom they are in a caring relationship or responsibilities to themselves to be attentive to their own care or treatment. Furthermore, contrary to current perceptions that children who are perceived to bear responsibilities (typically child carers of disabled parents or siblings) are somehow to be pitied or viewed as children in need, I contend we underestimate children by so viewing them. Colin Macleod discusses the concept of reciprocity of care within familial relationships and notes that as children mature they can play an important role in securing their parents interests.<sup>218</sup> He argues that we should value affective and partial familial relationships because they provide many of the human goods that

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<sup>215</sup> Noddings (n198).

<sup>216</sup> Cockburn (n121).

<sup>217</sup> Alderson (n1) 6.

<sup>218</sup> Colin Macleod, ‘Liberal Equality and the Affective Family’ in David Archard and Colin Macleod (eds) *The Moral and Political Status of Children* (2002 OUP) 216.

depend on partiality for their success. These relational responsibilities of children may apply not only to parents but also to siblings. Dwyer notes that the state may create and offer protection to sibling relationships, which he claims are ‘the most important relationships in the lives of some children and central to the lives of most, typically entailing emotional ties stronger than those with any other nonparent relatives, such as grandparents, aunts, uncles and cousins’.<sup>219</sup> The law does this by creating parent-child legal relationships with more than one child, but these rules require no consideration of whether it would be in the child’s best interest to have a legal relationship with a particular sibling.<sup>220</sup> Finally, this guideline would allow for an examination of any external factors which may influence the caring relationship such the capacities, resources and limits of the ‘one-caring’.

#### 4.2.3 - Guideline Three – Evaluation of the Social Context of Care.

Bridgeman’s Guideline Three is the ‘consideration of the social context of the care, such as cultural norms, beliefs and access to resources needed for care’.<sup>221</sup> I shall term this merely ‘evaluation of the social context of care’. This final guideline provides for a broader perspective beyond that which the courts may deem to be in the child’s medical best interests, by assessing the decision’s impact in it’s cultural, religious or social context. This context is likely to become increasingly important as the child grows older and it forms a more pervasive part of his identity.

The sixth facet reveals that neither a ‘best interests’ nor a rights based approach alone is the best way to meet the needs, or represent the interests of children. A welfarist

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<sup>219</sup> Dwyer (n180) 60.

<sup>220</sup> *ibid*

<sup>221</sup> Bridgeman (n13) 239.

approach will sometimes be necessary, but care should be alert to one that is cloaked in parental 'control'. The impact upon the child and those caring for him of external factors is relevant here and the importance of, for instance, religious belief, will need to be weighed against the child's medical interests. Yet this aspect of the child's relational self may be complex, as questions arise of potential 'undue influence', pressure on the child to please parents or conform with social or cultural expectations. At the same time, it is important not to over state this point, as it is true that adults and children alike are products, to a greater or lesser degree, of their upbringing and we are all influenced in our decision-making by a wide variety of factors. Nonetheless, a rights based approach *may* be necessary to reconcile the need to retain the primary bonds of care and affection with the justice requirements of fair treatment, by acting as a scrutinizing or tempering mechanism to the reach of care.

## **Section 5 – Children's Participation in Healthcare Decision-Making.**

### **5.1 - Children's Participation and Shared Decision-Making**

One of the most obvious differences in conceptualising the child in mid-childhood through an Ethics of Care framework is that because the child is an active participant in the relationship, there is also greater scope for fostering the maximum participation (that the child desires) within the decision-making process. John Eekelaar has expressed his concern that traditional welfare or rights approaches leave little scope to acknowledge a child's true views. Instead they often endorse an approach of 'coercive paternalism' by adult decision-makers.<sup>222</sup> In response, he proposes an approach which seeks a reconciliation between 'best interests' and children as possessors of rights -

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<sup>222</sup> John Eekelaar, 'The Importance of Thinking that Children have Rights' in P Alston, S Parker and J Seymour (eds) *Children, Rights and the Law* (Clarendon Press 1992).



that of ‘dynamic self-determination’.<sup>223</sup> Under this model, which Archard probably rightly claims is merely a reconstruction of the best interests test,<sup>224</sup> there is scope for the child to determine what their best interests are. It is a dynamic process in that, in line with the Ethics of Care, it is attentive to the continuous nature of the child’s development and his changing needs and experience. The goal is to ‘bring a child to the threshold of adulthood with the maximum opportunities to form and pursue life-goals which reflect as closely as possible an autonomous choice’.<sup>225</sup> However, herein lies the problem. Much like Joel Feinberg’s argument that children have a ‘right to an open future’,<sup>226</sup> Eekelaar’s model focuses on the person that the child is to become rather than the being that he is now. It gives priority to the attainment of adult ‘autonomy’ over present concerns. But postponing potentially limiting choices until adulthood, is nonetheless a choice, even one of inaction, which may have consequences for the child’s present reality which in turn may have an impact on the adult’s ability or opportunity to choose in the future. This model places too much emphasis on what the child is to become and as Archard notes ‘(...) it is the child choosing as the future autonomous adult who determines what choices should be made for her now by competent adults’.<sup>227</sup>

However, as discussed above, a model of relational responsibility based on my conception of a child through the Ethics of Care provides for participation of the present child. It is important to note that in advocating for greater participation of children, is not to necessarily argue for a diminution in family participation. Speaking

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<sup>223</sup> John Eekelaar, ‘The Interests of the Child and the Child’s Wishes: The Role of Dynamic Self-Determination’ (1994) 8 (1) *International Journal of Law, Policy and the Family* 42, 43.

<sup>224</sup> Archard (n142) 69.

<sup>225</sup> Eekelaar (n145) 53.

<sup>226</sup> Joel Feinberg, ‘The Child’s Right to an Open Future’ in W Aiken and H laFollette (eds) *Whose Child?* (Littlefield, Adams & Co 1980).

<sup>227</sup> Archard (n142) (2013) 69.

from the perspective of family inclusion in decisions concerning *adult* patients, O'Donovan and Gilbar question medical law's traditional conception of the individualistic patient whilst neglecting the input of their loved ones.<sup>228</sup> Of course in cases relating to children, the opposite can be said to be true, whereby the law *requires* family participation as parents make decisions in children's best interests, whilst the child as patient, remains the object rather than subject of the decision. Nonetheless, what children's cases do have in common with adults is that the focus remains individualistic, with little room for wider consideration of the needs or impact upon the family. The remedy, I suggest, would work equally well for children as it does for adults. Here O'Donovan and Gilbar suggest that patient participation be viewed as an exercise in 'relational autonomy' in order to facilitate a careful reconciliation of the tensions between patient autonomy and interdependence with intimates.<sup>229</sup> They note that the place of the family in decision-making should not be viewed merely as one to facilitate knowledge of the patient or as a means for patient recovery but as a '(...) collective with an end in itself (...)'.<sup>230</sup>

Arguing for greater participation of children in decision-making is clearly to respect their growing autonomy under a 'choice' model of rights and attempts to remedy the marginalization or neglect of children's right to participate, as granted under Article 12 UNCRC.<sup>231</sup> It also recognises the active part that children in mid-childhood may play in their relationships and in taking care of their own health. Although children's rights as the basis of a framework for decision-making are generally rejected by care

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<sup>228</sup> Katherine O'Donovan and Roy Gilbar, 'The Loved Ones: Families, Intimates and Patient Autonomy' (2003) 23 *Legal Studies* 332, 333.

<sup>229</sup> *ibid* 334.

<sup>230</sup> *ibid*

<sup>231</sup> Imelda Coyne, 'Children's Participation in Consultation and Decision-Making at Health Service Level: A Review of the Literature' (2008) 45(11) *International Journal of Nursing Studies* 1682.

ethicists as too individualistic and adversarial, I would suggest that they do have a place as a tool to enable responsibilities to be fulfilled and to be genuinely caring.<sup>232</sup> Equally under a welfare model, participation can be seen to be in a child's best interests. Indeed, it is a requirement of the statutory welfare checklist that as children grow in competence and understanding their wishes and feelings should be heard.<sup>233</sup> It may also be seen to promote the child's interest in encouraging the skills necessary for adulthood and to facilitate the opportunity to have a 'dry run' at adult decision-making.<sup>234</sup> However, under a model of 'relational responsibility' a child's participation is best viewed as a process of shared-decision-making between the healthcare professionals, the family, and the child as patient, which respects the impact of the decision on all who are in interdependent relationships.

## 5.2 - How Relational Responsibility fosters Children's Participation.

Each step of the care framework as detailed above, lends itself well to fostering children's participation in decision-making. First in terms of attentiveness to the child as an individual, viewing the child as vulnerable may carry with it multilayered consequences for decision-making. On one level, it may alert us to developmental immaturities, defects of rationality or emotional instabilities of this particular child, which may preclude autonomous decision-making, or even threaten participation. For those children who are deemed to be competent to make decisions and therefore on one level free from such vulnerabilities, in fact their vulnerabilities may be *magnified* through the process of decision-making, as they are opened up to new experiences and responsibilities.<sup>235</sup> On another level, a conception of the vulnerable child may

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<sup>232</sup> Herring (n2) 49.

<sup>233</sup> Children's Act 1989 s1.

<sup>234</sup> Fortin (n100) 7.

<sup>235</sup> Van Praagh (n23) 368.

merely flag up that all of us, adults and children alike, are want to make decisions in concert with others and that shared decision-making may enhance competence where it was previously lacking. This may attempt to redress the imbalance currently seen within the law, where on one hand a child who seeks to make atomistic decisions is treated with suspicion, yet on the other a child who seeks to make decisions influenced by others is seen as a cause for concern.<sup>236</sup>

The embodied child approaches the process of decision-making by placing the physical reality of their condition and its bodily consequences at the heart of the decision. It is within the body that the pain or comfort of treatment or care is felt. Likewise, it is the body that will respond to medication or strive to recover after surgery. Linking mind to body is the notion of mental satisfaction and sense of fairness at having being heard,<sup>237</sup> which is then conducive to bodily acceptance of treatment, even if the outcome does not favour the child's wishes. This can be compared to the mental anguish at having ones voice silenced and the corresponding bodily tension and resistance to treatment that may result from coerced treatments that may severely infringe upon the bodily and intellectual integrity of the child. As Alderson and Goodwin claim, forcing treatment on children as if they are 'unthinking or irrational beings' is misguided.<sup>238</sup>

Finally, a focus on the concrete reality of the child's as a being in her own right, in a real situation, allows for a consideration of the appropriate level of participation for that child. As a result of her empirical work, Priscilla Alderson suggests a

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<sup>236</sup> *ibid* 350.

<sup>237</sup> Archard (n142) 72.

<sup>238</sup> Alderson (n1) 306.

‘presumption of competence’ whereby a child should be regarded as competent unless there are clear reasons to remove that expectation, from the age of 5.<sup>239</sup> Such a presumption would have procedural force, in that it would direct adults to be mindful of the child’s potential to participate in decision-making.<sup>240</sup> Archard’s model however may be more useful, as it provides for greater subtlety in discerning the extent and context of the participation. He provides for three ways that the child may participate.<sup>241</sup> The first is ‘consultative’ where the child’s views can better help the adult decision-maker determine what is in the child’s best interests. The second is ‘contributory’ where part of what is in the child’s best interests itself is that the child should be permitted to participate in decision-making. The final option is that the child’s views carry ‘independent value’ in that it is a distinct source of knowledge, regardless of the final weight given to those views. This option is the only one that would seem to satisfy the right of participation envisioned under Article 12 of the UNCRC. If the child’s views are to be weighted, Archard raises the issue of how to identify the weight they may carry in a particular case, when even if the child’s views were taken very seriously because ultimately they were determinative or not, it would be impossible to discover merely by looking at the outcome.<sup>242</sup> The level and type of participation could be determined by the desires of the child and the complexity and gravity of the decision to be made. Options may range from complete deferral to parents, through to a process of shared decision-making with the child for instance, receiving information, expressing an opinion, choosing amongst options or

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<sup>239</sup> Alderson (n1) 74.

<sup>240</sup> *ibid* 75.

<sup>241</sup> Archard (n142) 64.

<sup>242</sup> *ibid* 71.

negotiating with parents,<sup>243</sup> to the child being autonomous in making the decision, if their maturity and experience justified this.

The Second Guideline would bring into focus the interconnected nature of the child's life and the importance of acknowledging the value, from the child's perspective, of the care that has been given in the past and what may be offered in the future.

Equally, because the happiness of the child is to some measure dependent on the quality of the relationships that she has with others, the impact of the decision on all those with whom the child is in relationship must be considered. As O'Donovan and Gilbar note '[w]here family members will be primary carers of the patient, their autonomy enters into the question, and their participation will be required in medical decisions'.<sup>244</sup> This links back with the concept of vulnerability, where at its most nuanced level, the vulnerability that arises when children, parents, siblings and other loved ones coexist in intimate relationships should be cherished as a good that promotes trust and personal growth. As discussed above, the vulnerabilities of the cared-for become the vulnerabilities of those that are caring for them. Accordingly, the child's attention may be turned, in an altruistic sense, to recognize the needs and wishes of those whom they are interconnected with. As Hardwig notes, 'to be part of a family is to be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself'.<sup>245</sup>

A second aspect of caring practice, is the knowledge that the child may have gained through their experience of their own health that may uniquely qualify them to

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<sup>243</sup> Victoria A Miller and Diana Harris, 'Measuring Children's Decision-Making Involvement regarding Chronic illness Management' (2012) 37 (3) *Journal of Pediatric Psychology* 292.

<sup>244</sup> O'Donovan and Gilbar (n228) 335.

<sup>245</sup> J Hardwig, 'What about Family?' (1990 March-April *Hastings Centre Report*).

participate. As Alderson and Montgomery argue that ‘ (...) however close parents are to their children, they cannot wholly share the insight into the personal impact of care which young patients gain through their own experience’.<sup>246</sup> Here their work is especially revealing as they note that contrary to the perceived fixed and linear progression of the developmental model, research<sup>247</sup> demonstrates that ‘[e]xperience is far more salient than age in determining children’s understanding’.<sup>248</sup> Studies by Alderson<sup>249</sup> have shown that seriously ill children, such as those with cystic fibrosis can show a ‘profound knowledge of severe illness, intensive treatment, the meaning of death and the value of life’ and are able to make sensible and considered decisions.<sup>250</sup> They were also able to cope with complicated and distressing information. Because of their daily intimate experience of living with a particular condition and the impact it has upon their relationships, such children have a unique knowledge of their own case.<sup>251</sup> Yet both the tests of competence found in legislation and case-law ignore experiential knowledge and rather are based on the premise that capacity is linked to knowledge and wisdom relating solely to medical and legal information. As a consequence many children are deemed to lack capacity to even participate in decision-making in a minimal way. However, Jane Fortin rightly highlights by way of caveat that ‘[a]lthough some children may, through experience, become competent to deal with the challenges that life throws up and able to make decisions in the face of pain, hardship and ill-health, this may be at considerable

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<sup>246</sup> Alderson (n104) 2.

<sup>247</sup> See M Bluebond-Langer, *The Private Worlds of Dying Children* (Princeton University Press 1987); C Clunies-Ross and R Lansdown ‘Concepts of Death, Illness and Isolation found in Children with Leukaemia’ (1988) 14 *Child: Care, Health and Development*, 373.

<sup>248</sup> Alderson (n104) 7.

<sup>249</sup> Priscilla Alderson, *Children’s Consent to Surgery* (Open University Press 1993).

<sup>250</sup> Priscilla Alderson (n1) 303.

<sup>251</sup> *ibid* 305.

psychological cost<sup>252</sup> and therefore, even though very young children are able to participate it may be questionable whether it is right that they *should* do so.

The final guideline of the consideration of the social context, should highlight the child's right to voice the religious or cultural dimension which may be important to them in relation to the decision that is to be made. Conversely here questions may arise of the potential for 'undue influence' or ability to freely chose when the child may be laboring under cultural expectation or religious indoctrination. Further, Barry Lyon's work assesses children's motives in participation in decision-making. He identifies that an expansive view of best interests, (of the kind that would be envisioned under a care orientation) would enable relational or altruistic motivations to be taken into account.<sup>253</sup> For example, in the case of inter-sibling bone marrow donation, he notes that such an action may be seen to be in the child's best interests by considering that the 'emotional bonds and psychological benefits' accruing to the child are sufficient in magnitude to outweigh any risk to their medical interests.<sup>254</sup> Such benefits could be increased self-esteem from helping others, continued companionship of the loved family member or increased status in the family for their donation.<sup>255</sup> However, I disagree with his thesis that relational or societal responsibility is an insufficient justification for altruistic action. Lyons' rationale is a denial that children have any duty in law to parents or siblings and the duty model's inability to take account of imbalances of power within the family.<sup>256</sup> Under the care model, there is no presumption of a legal duty upon children but rather a moral one, which acts as a component in a larger caring orientation, which may be used as an

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<sup>252</sup> Fortin (n100) 87.

<sup>253</sup> Barry Lyons, 'Obliging Children' (2011) 19 Medical Law Review 55 58.

<sup>254</sup> Lyons (n94) 375.

<sup>255</sup> Lyons (n253) 62.

<sup>256</sup> *ibid* 69.



interpretive tool of the legal duty of 'parental responsibility'. In addition, as noted above, care can act as a scrutinizing mechanism to identify and address power imbalances within relationships, which may influence the child's decision.

### **Concluding Thoughts**

In conclusion, it has been demonstrated in this chapter that conceptualizing the child and childhood through the Ethics of Care would produce a richer and more complete portrayal than through either the welfare or rights paradigm. Adopting a care orientation would allow us to see the child in the mid years of childhood, not as an incompetent infant but as vulnerable, relational, embodied 'being', who is endowed with valuable characteristics in his own right. Whilst still in need of protection and guidance, he also possesses powerful knowledge of his own embodied experiences, social circumstances and familial relationships. This child is capable not only of recognizing the care that he receives but also of undertaking some of the responsibilities of being 'one-caring' himself. Placing this conceptualization of the child into the concrete reality of healthcare decision-making, Jo Bridgeman's 'relational responsibility' provides a fitting framework to address how the characteristics, knowledge and relationships of the child can be accommodated within healthcare decision-making.

**CHAPTER 3**

**BEST INTERESTS, CHILD COMPETENCE AND**

**JUDICIAL DECISION-MAKING IN HEALTHCARE**

**LAW**

*‘No one can dictate the treatment to be given to the child, neither court, parents nor doctors. There are checks and balances. (...) The inevitable and desirable result is that choice of treatment is in some measure a joint decision of the doctors and the court or parents’.*<sup>1</sup>

**Introduction**

Parental Responsibility is not without limits. Indeed, the most widely acknowledged limitation of parents’ responsibility for their child’s health is the notion that their decision-making must concur with the child’s ‘best interests’.<sup>2</sup> There may be times when parents, healthcare professionals or children themselves are confronted with a situation so difficult, so novel or where disagreement is so entrenched, that the only option is resort to the courts in order to seek some form of resolution.<sup>3</sup> If they find that children in mid-childhood (as they almost invariably do), fail to reach the required standard to be deemed *Gillick* competent,<sup>4</sup> the courts are tasked with making a decision in accordance with the child’s best interests. Such cases of course, represent

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<sup>1</sup> *Re J (A Minor)(Wardship: Medical Treatment)*(1990) 2 WLR 140, 145.

<sup>2</sup> Giles Birchley, ‘What limits, if any, should be placed on a parent’s right to consent and/or refuse to consent to medical treatment for their child?’ (2010) 11 Nursing Philosophy 280.

<sup>3</sup> Andrew Bainham and Stephen Gilmore, *Children: The Modern Law* (4<sup>th</sup> edn, Family Law 2013) 351.

<sup>4</sup> *Gillick v West Norfolk & Wisbech AHA* [1985] UKHL7; [1986] AC 112 – See Chapter 2

extreme examples and are generally not reflective of the daily decision-making that resides in the informal and relational processes of the family or the semi-formal ones of the healthcare institution. However, an appeal to a ‘disinterested’ third party in the form of the judge may provide for space and clarity often obscured by the intimacy of the familial and clinical setting. At its best, the judicial process will seek, as far as possible, to find some kind of consensus between *all* the parties concerned, as demonstrated in the quote by Lord Donaldson in *Re J*, above.<sup>5</sup> What is perhaps most telling about that statement however, is the complete absence of the child as a participant in the decision-making process.

A resort to the law is not without its problems. When interpreting best interests the courts seem to prefer generalistic pronouncements of decisional compliance with the apparently self-evident, ‘welfare’ or ‘best interests’ of the child. For cases that are brought to court as an application for a Section 8 Order under the Children Act 1989,<sup>6</sup> the court is required to apply the Welfare Principle,<sup>7</sup> and advised to consider the factors contained in the Welfare Checklist.<sup>8</sup> However a clear articulation of the relevance and weight of these individual welfare factors is often lacking.<sup>9</sup> Further, judicial decision-making in the context of children’s healthcare has been, often rightly, criticised as overly atomistic,<sup>10</sup> inevitably deferential to medical opinion,<sup>11</sup> a

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<sup>5</sup> *Re J* (n1)

<sup>6</sup> ‘Section 8 Orders’ under the Children Act 1989 encompass ‘Child Arrangements Orders’, ‘Prohibited Steps Orders’ and ‘Specific Issue Orders’.

<sup>7</sup> Children Act 1989 s1(1).

<sup>8</sup> *ibid* s1(3).

<sup>9</sup> It is important to note however that most cases are brought to the court as an application to exercise the court’s inherent jurisdiction. In these cases the relevant test is that ‘the first and paramount consideration is the well being, welfare or interests (each expression occasionally used, but each, for this purpose, synonymous) of the human being concerned’ as per Lord Hailsham in *Re B (a minor)(Wardship: Sterilisation)* [1988] AC 199 [202]. The welfare checklist is not applied in these cases.

<sup>10</sup> Jonathan Herring, ‘Where are the Carers in Healthcare Law and Ethics?’ (2006) 27 *Legal Studies* 51, 65.

hostage to pressures of time,<sup>12</sup> lacking in long-term perspective<sup>13</sup> and absent any consideration of realltionalty.<sup>14</sup>

The aim of this chapter is to assess whether the Ethics of Care is a fitting and useful tool to aid in the judicial interpretation of the best interests test and the *Gillick* competence threshold in healthcare cases and ask whether it may successfully address some of the traditional criticisms of these approaches, particularly in relation to children in mid-childhood. As will be demonstrated in the systematic review below, because the courts very rarely engage with *Gillick* competence with this age group, my prime focus will be upon best interests. I will begin with an exploration of the benefits and pitfalls of best interests through an examination of the strength of the five key criticisms that are made of it. I shall argue that the retention of the best interests test is the pragmatic choice but that the way it is currently utilised is insufficient to either recognize the child's relational self or foster her participation. The Ethics of Care framework developed in Chapter 2 will then be presented as a potential solution to these shortcomings. Next I will consider the process of judicial interpretation of best interests and child competence and question the position of judges as the final arbiters in these cases. This will be followed by an examination of the prevalence and persuasiveness of relational reasoning. The second half of the chapter will consist of a systematic review of the case law relating to healthcare of children in mid-childhood

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<sup>11</sup> Muireann Quigley, 'Best Interests, the Power of the Medical Profession and the Power of the Judiciary' (2008) 16 Health Care Anal 233.

<sup>12</sup> John Harrington, 'Deciding Best Interests: Medical Progress, Clinical Judgment and the "Good Family"' [2003] 3 Web JCLI <<http://webjcli.ncl.ac.uk/2003/issue3/harrington3.html>> <Accessed 18 March 2014>

<sup>13</sup> Jo Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (CUP 2007).

<sup>14</sup> Jonathan Herring, 'Farewell Welfare?' (2005) 27 Journal of Social Welfare and Family Law 159, 169.

over a 26-year period.<sup>15</sup> The purpose of the review is to test the validity of the criticisms highlighted and assess whether its use might have altered the decision-making process or indeed the outcome of these cases.

## **Section 1 – Retaining the ‘Best Interests’ Test – The Pragmatic**

### **Choice?**

#### **1.1 - The Benefits and Five Criticisms of Best Interests**

The best interests test or welfare principle<sup>16</sup> is at once well regarded and fiercely criticized. Birchley observes that both within legislation and professional practice, there is a ‘remarkable the degree of consensus’ around the concept that parents should make decisions on behalf of children on the basis of their best interests.<sup>17</sup> Indeed, ‘best interests’ has been described as the ‘golden thread’ that runs through UK child law.<sup>18</sup> Praise for the principle appears to be rooted in the notion that by placing the child’s welfare as the paramount consideration, it becomes a powerful tool to protect and fully promote the interests of the ‘vulnerable’ child<sup>19</sup> and may act as a necessary corrective to the dominance of adult-centred concerns.<sup>20</sup> As noted in Chapter 2,<sup>21</sup> from a care perspective the best interests test holds the promise of flexibility,<sup>22</sup> which may be especially fitting for healthcare decision-making for children in mid-childhood.

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<sup>15</sup> 1990-2016.

<sup>16</sup> The Children Act 1989 refers to the welfare principle whilst in the case-law, in International Provisions and in professional policy documents reference is made to ‘best interests’. The two terms appear to be used interchangeably. I shall primarily use best interests but any reference to welfare should be construed with the same meaning.

<sup>17</sup> Birchley (n2) 282. Again it is important to note that parents are not required to adhere to the Welfare Principle nor apply the Welfare Checklist in their decision-making. Only in the event that the parents’ decision should be challenged and placed before the court in an application for a Section 8 Order would the court use the Principle and Checklist in independently adjudicating on the matter in question.

<sup>18</sup> Lord Fawsley (Wednesday 31 January 2007) House of Lords Debates, Hansard.

<sup>19</sup> Herring (n14) 159.

<sup>20</sup> Sarah Elliston, *The Best Interests of the Child in Healthcare* (Routledge-Cavendish 2007) 15.

<sup>21</sup> Chapter 2.

<sup>22</sup> Herring (n14) 169.

However, Waite LJ's comments in *Re T*<sup>23</sup> that 'the law's insistence that the welfare of a child shall be paramount is easily stated and universally applauded, but the present case illustrates, poignantly and dramatically, the difficulties that are encountered when trying to put it into practice',<sup>24</sup> demonstrate the reality that clarity in the process is notoriously difficult to achieve.<sup>25</sup> The details of these criticisms may be categorised under 5 main heads:

### 1.1.1 - The Nature of 'Best Interests'

The essence of this first criticism resides in a two-fold claim that 'best interests' remains a vague concept. The first strand addresses the difficulties of interpretation of the term 'best interests'; begging questions such as what is 'best', by whose standards and in what context is this to be judged, and to which 'interests' should a judge have regard? However, the presence of the seven factors of the Welfare Checklist contained in section 1(3) of the Children Act 1989, as discussed in Chapter 2 above,<sup>26</sup> does attempt to provide some structure to the assessment in the context of an application for a Section 8 Order.<sup>27</sup> The second strand of the criticism concerns the absence of detailed consideration of the weight and importance of these welfare factors, or the elements that may go into a 'balance sheet' type of analysis of best

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<sup>23</sup> [1997] 1 All ER 906, [1997] 1 WLR 242.

<sup>24</sup> *ibid* 916.

<sup>25</sup> *ibid* 916.

<sup>26</sup> Chapter 2.

<sup>27</sup> Children Act 1989 s1(3) provides the 'welfare checklist'. Its 7 factors are: (a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding); (b) his physical, emotional and educational needs; (c) the likely effect on him of any change in his circumstances; (d) his age, sex, background and any characteristics of his which the court considers relevant; (e) any harm which he has suffered or is at risk of suffering; (f) how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs; (g) the range of powers available to the court under this Act in the proceedings in question.

interests.<sup>28</sup> This is evidenced, according to Birchley, by the fact that individual factors go largely unacknowledged in the case law.<sup>29</sup>

Certainly it would be fair to note that Statute Law provides no guidance in relation to the order of priority or weighting of any of the factors. Additionally it may be claimed that the requirement of ‘best’ is practically unrealistic when applied to decision-making in the context of family life; amplified as it is by doubts that the best interests of the child must always remain *paramount*.<sup>30</sup> This tension is uncovered by McGuinness who, drawing on Archard’s work,<sup>31</sup> notes that best interests can be both ‘unfeasibly demanding’ in that its sole focus is on the unconnected individual, yet at the same time ‘practically indeterminate’ as its terminology is wholly unclear.<sup>32</sup> In relation to unfeasible demands, Birchley’s observation that in daily life the State permits families to subject their children to the consequences of decisions that may not be in their medical best interests such as eating an unhealthy diet or being affected by passive smoking reveals the hypocrisy in demanding such compliance when a problem is before the courts. Here, I concur with Baines’ argument that the result of the child’s welfare being the paramount consideration may be that the parents are then unable to consider their own needs or those of other members of the family, thereby undermining the integrity of the structure of the family that is so integral to the wellbeing of the child.<sup>33</sup>

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<sup>28</sup> In some of the cases the judges have adopted a ‘balance sheet’ interpretation of best interests. This approach was first presented by Thorpe LJ in the adult incapacity case of *Re A (Male Sterilisation)* [2000] 1 FLR 549, 560 and its use can be seen in the mid-childhood case of *In the Matter of X (A Child)* [2014] EWHC 1871 (Fam) para 16.

<sup>29</sup> Birchley (n2) 282.

<sup>30</sup> Elliston (n20) 17.

<sup>31</sup> David Archard, *Children: Rights and Childhood* (Routledge 1993).

<sup>32</sup> Sheelagh McGuinness ‘Best Interests and Pragmatism’ (2008) 16 Health Care Anal 208, 209.

<sup>33</sup> Paul Baines ‘Medical Ethics for Children: Applying the Four principles to Paediatrics’ (2008) 34 Journal of Medical Ethics 141.

### 1.1.2 - Judicial Deference to Medical Opinion.

The second criticism addresses the disproportionate weight traditionally given in healthcare cases to medical opinion. Brazier contends that conflicts between parents and paediatricians that result in court action are nothing new.<sup>34</sup> Stemming back to the case of *R v Arthur* in 1981,<sup>35</sup> the early judgments essentially employed the professional medical standard – the *Bolam* test,<sup>36</sup> for determining best interests, with little scope for relational considerations or alternative opinions.<sup>37</sup> Judicial deference to medical opinion, Elliston argues, was employed in order that judges might bring ‘scientific legitimacy’ to their judgments.<sup>38</sup> Birchley contends that the courts have fixated on the single, clinical view of best interests, as a means ‘to lever parental doubts’,<sup>39</sup> whilst Bainham and Gilmore see its purpose not as ordering the medical team to act against their clinical judgment but rather to *reinforce* their judgments’.<sup>40</sup> However, Braizer claimed back in 2004, that there was some move in the case law towards ‘de-bolamising’ the best interests test.<sup>41</sup> Quigley confirms a trend in more recent cases away from medical deference (as illustrated in the cases discussed in the systematic review, below) but sees such a development as a ‘worrying’ move towards judicial deference - ‘substituting one professional standard for that of another: their own’.<sup>42</sup>

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<sup>34</sup> Margot Braizer in ‘Commentary : An Intractable Dispute: When Parents and Professionals Disagree’ [2004] Med L Rev,413.

<sup>35</sup> *R v Arthur* (1981) 12 BMLR 1.

<sup>36</sup> *Bolam v Friern Hospital Management Committee* (1957) 2 All ER 118. This case lays down the test for the required standard of reasonable care as being in accordance with a ‘responsible body of medical opinion’.

<sup>37</sup> Quigley (n11) 234.

<sup>38</sup> Elliston (n20) 18.

<sup>39</sup> Birchley (n2) 281.

<sup>40</sup> Bainham (n3) 342.

<sup>41</sup> Braizer (n34)

<sup>42</sup> Quigley (n11) 236.



### 1.1.3 - Judicial Paternalism: Stifling Children's Participation?

The third criticism relates to the claim that judges have been overly paternalistic, with the consequence that they do not lend sufficient weight to a child's views nor foster their participation. This is observed not only when dealing with very young or very disabled children but also those who are in mid-childhood and beyond. There is an accusation that the seven welfare criteria, when used, are susceptible to the bias and prejudice of the decision-maker who is interpreting them.<sup>43</sup> Diduck is perceptive in noting that the weight given to the wishes of the child depends upon adult (judicial) constructions of the child's competency and level of understanding.<sup>44</sup> Therefore it follows that a child is more likely to be construed to be of the requisite age and understanding if her views conform to adult ideas of welfare.<sup>45</sup> A resistance to this type of paternalistic construction of welfare has been seen in recent debates relating to adults with disabilities. In April 2014, the Committee on the Rights of Persons with Disabilities stated that best interests (such as found in legislation such as the Mental Capacity Act 2005) was incompatible with Article 12 of the UN Convention on the Rights of Persons with Disabilities and for incapacitated persons should be replaced with the test of the 'best interpretation of the will and preferences' of that individual'.<sup>46</sup> It would be intriguing to see if such an approach could be applied to children.

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<sup>43</sup> David Archard, 'Children, Adults, Best Interests and Rights' (2013) 13(1) Medical Law International 55, 56.

<sup>44</sup> Alison Diduck, *Law's Families* (LexisNexis Butterworths 2003) 92.

<sup>45</sup> *ibid* 92.

<sup>46</sup> Rosie Harding, *Duties to Care: Dementia, Relationality and the Law* (CUP 2017).

#### 1.1.4 - The Absence of Relational Reasoning.

The fourth criticism touches both the interpretative and weighting aspects of best interests. This concerns the absence in both the welfare criteria approach and in the inherent jurisdiction jurisprudence, of any explicit reference to the quality or strength of the child's relationships or the impact that the decision may have upon them. The strict interpretation of the test is an individualistic one, which seeks to 'maximize' the child's interests largely absent any relational reasoning. Yet such maximization of individual interests may lead to outcomes that are damaging to relationships and thereby damaging to the child's, equally important, relational interests.

#### 1.1.5 - Shortsightedness

The fifth criticism is that in healthcare cases the courts are often under great constraint of time due to the pressures of emergency situations,<sup>47</sup> and as a consequence best interests may be construed in a very limited 'shortsighted' manner. Such constructions consider only the child's present circumstances and thus neglect to accord sufficient weight to the important aspects of historical caring practices or future impact of the decision.<sup>48</sup>

### 1.2 - Modifying or Replacing Best Interests

Because of these criticisms there have been academic calls for the modification, or even replacement of the best interests test. Archard tackles both the interpretative and weighting strands of criticism by adopting a 'care-type' approach in positing a move away from a strict construction of best interests and rejecting the implausible 'maximizing' of a child's interests. Rather, he interprets the principle as one requiring

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<sup>47</sup> Harrington (n12).

<sup>48</sup> Jonathan Herring, *Family Law* (5<sup>th</sup> edn, Pearson Education Ltd 2011) 40.

the well-being of the child to be no more than a consideration and a constraint.<sup>49</sup> Such a dilution in strength has also been advocated by Eekelaar, who argues that in order to protect “family life” as enshrined in Human Rights conventions, there needs to be some reform of the domestic law away from a sole focus on the child’s best interests. This reform would also tackle weighting issues by including a balancing of children’s well-being with adult and familial interests, even if such rebalancing might result in less than optimal results for children.<sup>50</sup>

Most radically, Elliston proposes abandoning the best interests test altogether and replacing it with the test of ‘significant risk of serious harm’, as the threshold for state intervention. Short of this, she argues, decision-making should be left in the hands of the parents, who would be free to decide which of the interests of the child to promote.<sup>51</sup> Elliston’s work has a flavor of the ‘least detrimental alternative’ proposed by Goldstein et al,<sup>52</sup> which is presented as a more pragmatic and measurable test in circumstances where the continual demand for ‘best’ is unattainable.<sup>53</sup> Indeed, Elliston’s rationale ties in with Birchley’s argument discussed above, in that she claims that ‘[t]o go further usurps the legitimate authority and function of parents and creates inconsistency in the expectation of what is within the scope of parental decision-making’.<sup>54</sup> A positive aspect of Elliston’s approach is that there is greater

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<sup>49</sup> Archard (n43) 56.

<sup>50</sup> John Eekelaar, ‘Children between Cultures’ (2004) 18 International Journal of Law, Policy and the Family 178, 186-7.

<sup>51</sup> Elliston (n20) 3.

<sup>52</sup> Joseph Goldstein, Albert Solnit, Sonja Goldstein and Anna Freud, *The Best Interests of the Child: The Least Detrimental Alternative* (Free Press 1996).

<sup>53</sup> Patricia Hansen and Frank Ainsworth, ‘The ‘Best Interests of the Child Thesis’: Some Thoughts from Australia’ (2009) 18 Int J Soc Welfare 431, 437.

<sup>54</sup> Elliston (n20) 2.

protection for the range of reasonable decisions that a parent might make and for the parental task of balancing and negotiating the various interests of the family.<sup>55</sup>

Yet, powerful though elements of all the arguments above are, I would reject going as far as Elliston in abandoning best interests - indeed she acknowledges that her solution is unsatisfactory and that it is 'easier to criticize the principle than to come up with an alternative'.<sup>56</sup> Her 'significant harm' threshold, although in some ways consistent with the State's largely laissez-faire approach to much of informal parental decision-making, raises more questions than it answers. For example, the judgment of both the harm threshold and parental reasonableness would be just as open to criticism of subjective decision-making as is the current best interests test. On the threshold point does 'serious harm' refer only to physical danger or would it include threats of a psychological kind, as have been highlighted in recent debates around the impact of emotional neglect.<sup>57</sup> Further, how are spiritual harms to be weighed and how would it be possible to reconcile competing claims of physical versus spiritual harm as seen in the Jehovah's Witness cases? Additionally, if decisions under the threshold are left to parental reasonableness, some assessment of best interests will nonetheless remain albeit on the part of the parents rather than the courts.

### 1.3 - Best Interests viewed through the Lens of Care

I agree with McGuinness that the retention of the best interests principle is the pragmatic choice.<sup>58</sup> Such a view sits well with a care approach, in that it posits a test with a powerful history but which retains enough flexibility to take a 'case-by-case' approach to individual problems without showing an excessive desire to formulate

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<sup>55</sup> *ibid* 37.

<sup>56</sup> Elliston (n20) 287.

<sup>57</sup> See for example Ruth Gardner, *Developing an Effective Response to Neglect and Emotional harm to Children* (NSPCC Jan 2008).

<sup>58</sup> McGuinness (n32) 208.

legal principles'.<sup>59</sup> This allows for the discovery of the 'best' within contextual and comparative decision-making.<sup>60</sup> However, I *am* persuaded that the principle could be reconfigured, both in terms of interpretation and the weighting along the lines suggested by Archard and Eekelaar, above. On the first strand, Harrington rightly points out that the principle could be interpreted as a 'guiding standard' which points up relevant factors without dictating a particular outcome,<sup>61</sup> and allows judges to 'fashion and refashion new criteria of best interests'.<sup>62</sup> Further, such a construction would provide the space to ask how far parents and family members should be expected to sacrifice their own interests in order to satisfy the best interests test- a question which Morris notes has been consistently avoided because of the focus on an individualistic rendering of the test.<sup>63</sup> A refashioning would represent a more 'honest' portrayal, for both the child and other family members, of the reality of living in relation with others, as illustrated by Archard:

[a] parent has a legitimate interest in leading a certain kind of life that is not reducible to what is best for its child. It is also arguable - though contentious- that the parent has an interest in promoting the value of the family as such that may - subject to the guarantee of a child's essential interests - compromise the child's best interests.<sup>64</sup>

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<sup>59</sup> Nigel Lowe and Stavinder Juss, "Medical Treatment- Pragmatism and the Search for Principle" [1993] 56 Modern Law Review 865, 868, 870.

<sup>60</sup> McGuinness (n32) 11.

<sup>61</sup> Harrington (n12).

<sup>62</sup> *ibid*

<sup>63</sup> Anne Morris, 'Selective treatment of Irreversibly Impaired Infants: Decision-Making at the Threshold' (2009) 17(3) Med Law Rev 347, 353.

<sup>64</sup> Archard (n43) 60.

Here, we can see that taking an expansive relational view of best interests, which accommodates the interconnected nature of family relationships, may also expose the fact that the strict construction<sup>65</sup> sometimes acts to obscure the effect upon the individual needs of the adults in the relationship, for instance on their opportunities for employment or the integrity of their moral or religious principles. On the second strand of the weighting, Archard's vision provides for a holistic balancing of the family's interests. Ross has presented such a vision, where she argues that certain compromises of the individual child's maximized best interests are permissible in order to satisfy a broader *family* vision of the good.<sup>66</sup> Flekkoy and Kaufman go further by suggesting that there may also be situations where the competing interests of justice or society should deserve at least equal consideration or even greater emphasis than the best interests of the child.<sup>67</sup> Whilst it is clear that the child's *essential* interests should be guaranteed (not only as against whole family interests but also adult ones), I agree with Archard, Ross, and Flekkoy and Kaufman, that there may be times when the preservation of adult, familial or societal interests is more significant than the upholding of the individual child's best interests, even as viewed within a relational context. I think that a care framework would be better able to facilitate this.

Using the factors of the Welfare Checklist as an illustrative basis, I suggest that adopting the Ethics of Care model developed in Chapter 2 as an interpretative framework, is a means of refashioning best interests to take account of relational context. It could avoid claims of practical indeterminacy by clearly articulating the weight and relevance of each welfare criterion and thus subvert charges that without

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<sup>65</sup> Morris (n63) 353. She refers to the judgment of Lord Donaldson in *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33.

<sup>66</sup> Laine Freedman Ross, *Children, Families and Healthcare Decision-Making* (OUP 1998).

<sup>67</sup> MG Flekkoy and N Kaufman, *The Participation Rights of the Child: Rights and Responsibilities in Family and Society* (Jessica Kingsley Publishers 1997) 45.

further quantification best interests is at best an ‘empty mantra’,<sup>68</sup> and at worst a screen to disguise the prejudice or paternalism of decision-makers. Using this framework, the courts could engage more meaningfully with the factors of the welfare checklist or be more transparent when undertaking a ‘balancing exercise’. Its first task is to be attentive to the child as an individual and in terms of welfare factors, it could draw upon factor b – the physical, emotional and educational needs of the child, and factor d – the age, sex, and background and other relevant characteristics. Looking at these through a lens of care would eschew generalisations or abstract notions of how a child of a particular age or sex for example, would be expected to comprehend or respond to their situation.<sup>69</sup> Rather it would place the child’s background first and foremost in the context of her specific relationships, cultural identity and religious commitments. Her physical, emotional and educational needs could be viewed as relational by acknowledging both her inherent vulnerability and need for close relationships, and her embodied experience of her medical condition and treatment.

The second consideration requires an examination of the history of caring practice. This could encompass factor a – the ascertainable wishes and feelings of the child, and factor c– how capable the parents or carers of the child are at meeting her needs. In response, a care approach would place the child and her potential for participation as a key concern in the decision-making process. A relational view would reveal how participation can be facilitated, in accordance with the child’s desire, abilities and the gravity of the decision, by fostering an appropriate exchange of information and encouraging collaborative decision-making in the context of the child’s relationships.

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<sup>68</sup> Brazier (n34) 4.

<sup>69</sup> Helen Reece, ‘The Paramountcy Principle. Consensus or Construct?’ in Sonia Harris-Short and Joanna Miles (eds), *Family Law Text, Cases and Materials* (OUP 2007).

Further it would closely examine and give most weight to the opinions of those who had gained experience through past emotional connection and practical action and so, in Brazier's terms, would 'prioritise the picture of the child as daughter rather than the infant as a patient'.<sup>70</sup> This rebalancing would give credence to Birchley's contention that '[b]y giving each of these important contributions the acknowledgment it deserves, we might listen to all the voices in a child's life rather than just the voice that speaks most loudly'.<sup>71</sup> Collaborative decision-making would not be treated with the suspicion of undue influence, but would be welcomed as a necessary facet of facilitating the child's competence and respecting their relationality.

The third and final requirement is to evaluate the social context of care. Here factor f – the likely effect on the child of any change of circumstances, factor e – any harm which she has suffered or is at risk of suffering, and factor g – the range of powers available to the court, would be relevant. The court would certainly give weight to the medical opinion, particularly as the focus of the case will concern the child's medical care or treatment, yet it will remain but *one* view to be considered in the overall relational assessment of what is 'best'. Rather, the court would start by examining the future impact of the decision upon care within intimate relationships and conclude with an assessment of the wider implications within the child's religious or cultural community and indeed, society itself. The practical application of this holistic view of 'best' has been demonstrated within cases such as *Ashan v University Hospitals Leicester NHS Trust*.<sup>72</sup> The case concerned the palliative care of an incapacitated woman who the court held should be cared for at home in accordance with the wishes

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<sup>70</sup> Brazier (n34) 5.

<sup>71</sup> Birchley (n2) 284.

<sup>72</sup> [2006] All ER (D) 451 (Jul).



of her family and practices of her culture and Muslim faith. This was despite the fact that ‘no tangible benefits (...) are likely to flow from a recognition of those wishes’.<sup>73</sup> Another example is seen in the work of Coggon et al on the topic of non-heart-beating organ donation.<sup>74</sup> Here they argue that some deviation of clinical practice, such as the administration of drugs in order to maximize the chances of a successful donation, may be justified as being compatible with the best interests of those who have clearly expressed their wish to become an organ donor. They contend that despite such practices being not strictly in accordance with medical welfare, the patients’ best interests are served by also considering their ‘ethical, social, moral, spiritual and religious values’.<sup>75</sup>

This broader view also encompasses the difficult questions of the ‘dark side’ of care, with Archard and Macleod arguing for a more complex portrayal of the welfare model, which consequently holds that it is no longer possible to view the relationship between children and those who are responsible for them as necessarily harmonious.<sup>76</sup> Rather, it creates the imperative to look deeper to understand children’s interests and to ‘explore how the conceptualization of children’s interests affects the character of the moral claims they have’.<sup>77</sup> If this scrutiny of the quality and longer-term impact of those relationships reveals abuse, coercion or domination,<sup>78</sup> then the court can turn to its full range of powers to seek a solution. As discussed in Chapter 2, Waldron’s

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<sup>73</sup> *ibid* para 56, Hegarty J

<sup>74</sup> John Coggon, Margaret Brazier, Paul Murphy, David Price & Muireann Quigley, ‘Best Interests and Potential Organ Donors’ (2008) 14 (336) *BMJ* 1346.

<sup>75</sup> *ibid*

<sup>76</sup> David Archard and Colin Macleod, ‘Introduction’ in David Archard and Colin Macleod (eds) *The Moral and Political Status of Children* (2002 OUP) 4.

<sup>77</sup> *ibid*

<sup>78</sup> Herring (n48) 35.

suggestion is useful here as rights may be employed as ‘(...) a fallback and security in case other constitutive elements of a social relationship ever come apart’.<sup>79</sup>

## **Section 2 - Judicial Interpretation of the Child’s Welfare.**

### **2.1- Questioning the Role of the Judge.**

Before moving on to the practical operation of the test, it may be useful to take an overview of the role of the judge. Fox and McHale have questioned how well placed judges are to make complex healthcare decisions.<sup>80</sup> A key objection, as noted above, has been judicial deference to medical opinion. Further, in children’s healthcare cases the judge may take on some of the functions of a hospital ethics committee or operate as a mediator between the parents and the healthcare professionals.

Whilst it is fair to say that many parents may feel relieved to have the burden of reaching the decision removed from them, I concur with Brazier’s observation that in such situations the judge may not ‘command total confidence’ of the parents, as unlike the mediator, his role is ultimately to make the final decision.<sup>81</sup> The adoption of the traditional atomistic model of adjudication entails a removal of power from the parents, with a resultant sense that they are being deprived of ‘their’ child.<sup>82</sup> I would go further here, to consider the impact on the child, who as the subject of the decision, is often divested of both their voice and the control over their own body.

Yet, whilst it *is* true that judges lack both the medical knowledge of the healthcare professional and the intimate personal, social and cultural knowledge of the parents,

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<sup>79</sup> Jeremy Waldron, *Liberal Rights: Collected Papers 1891 - 1991*(CUP 1993) 374.

<sup>80</sup> Marie Fox and Jean McHale, ‘In Whose Best Interests?’ (1997) 60(5) Med L Rev 700, 708.

<sup>81</sup> Brazier (n34) 6.

<sup>82</sup> *ibid*

they *are* expert in weighing up multiple viewpoints and finding decisive resolutions to often, very difficult problems, as noted by Hedley J in *Wyatt*:

(...) whilst the judge will be more aware than anyone of his own limitations in deciding as profound an issue as this, a decision there simply has to be. It may well be that an external decision is in the end a better solution than the stark alternatives of medical or parental veto.<sup>83</sup>

However, Jonathan Montgomery claims that the action of law upon medical dilemmas is one of ‘de-moralisation of medicine’.<sup>84</sup> He fears that the scope for moral reflection and action is being reduced by patients’ quests for choice and demands for the respect of individual autonomy.<sup>85</sup> Certainly there remains a tension between this conception of the role of the judge as facilitator of an ‘amoral commitment to choice and consumerism’<sup>86</sup> and the relational approach. This not only acknowledges judicial subjectivity but encourages it in the context of the many viewpoints brought to bear on the decision-making process, as exemplified in the role of ‘caring justice’ discussed in s 2.3 below.

## 2.2 - Judicial Interpretation of the Best Interests Test

We might question whether the judge is best placed to make decisions in disputes over children’s healthcare (see section 2.3 below). However, it must be acknowledged that there does need to be a final arbitrator, and if we accept that this is to be the judge, it is imperative to examine the link between the views and experiences of that

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<sup>83</sup> *Re Wyatt (A Child) (Medical Treatment: Parent’s Consent)* [2004] EWHC 2247, Para 4.

<sup>84</sup> Jonathan Montgomery, ‘Law and the Demoralisation of Medicine’ (2006) 26(2) *Legal Studies* 185, 189.

<sup>85</sup> *ibid* 186.

<sup>86</sup> *ibid*

judge and his or her interpretation of best interests. As Fox and McHale observe ‘(...) the operation of the best interests test cannot be abstracted from the issue of who decides’.<sup>87</sup> The first point here relates to how the judge conceptualizes the child. Bridgeman queries the impact that the traditional portrayal of the child; what I described as the ‘romantic developmental’ view in Chapter 2,<sup>88</sup> has on the judges’ understanding of the child’s welfare. I concur with her fears that ‘the obligation imposed upon judges to make hard choices is hindered, not helped, by the legal framework’.<sup>89</sup> Painting a picture of the child as ‘vulnerable and dependent and in need of protection, including from their parents (...)’, creates an adversarial view which feeds into the judicial interpretation of best interests.<sup>90</sup> Further, as Skivenes observes, determining best interests is about making normative decisions about what is right for a child via a process of ‘predicting results and consequences that are difficult to estimate’.<sup>91</sup>

Against this backdrop, the second point relates to the interpretation of the welfare principle, when it is used, as contained in the legislation.<sup>92</sup> Whilst it is true that the process of determining best interests seeks to be a ‘particularistic-not a universal-assessment’,<sup>93</sup> it is important to note that there is no clear guidance as to which of seven criteria might be relevant in a particular case, nor any instruction as to the order of consideration or the weight to be given to each.<sup>94</sup> Although such an approach appears to be in accordance with the subtle flexibility and rejection of abstract

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<sup>87</sup> Fox (n79) 708.

<sup>88</sup> Chapter 2.

<sup>89</sup> Bridgeman (n13) 155.

<sup>90</sup> *ibid* 107.

<sup>91</sup> Marit Skivenes, ‘Best Interests: Rational Reasoning or Subjective Presumption?’ (2010) 53 (4) *Acta Sociologica* 339, 340.

<sup>92</sup> Children Act 1989 s1(3).

<sup>93</sup> Bridgeman (n13) 102.

<sup>94</sup> Jennifer Schweppe, ‘Best to Agree to Disagree? Parental Discord, Children’s Rights and the Question of Immunization’ (2008) 37(2) *CLWR* 147, 152.

principle prized by the Ethics of Care, it also leaves scope for little more than that which Harrington deems ‘the intuitive sense of reasonableness of the deciding judge’.<sup>95</sup> Also, as McGuinness stresses, there is no guidance as to whether best interests should be judged at an individual or policy level.<sup>96</sup> If policy considerations *are* entering the equation, as allowed for under a care framework, it is essential to recognize that judges are likely to start from different moral premises, intuitions or priorities and may conclude with different predictions of the likely consequences.<sup>97</sup> One solution is to retain a particularist approach but make it imperative that judges are clearer about which factors they deem relevant in each case and the weight each bears. In particular if taking a relational view, it is imperative that there is clarity as to the meaning of *caring* and the weight ascribed to the views of carers.<sup>98</sup>

### 2.3 - Judges and “Caring Justice”.

Under an Ethics of Care framework, the role of the judge would be seen as but *one* source of expertise, in conjunction with that of healthcare professionals, parents/carers and the child. Here I concur with Bainham and Gilmore’s assertion regarding the dangers of assuming there must be a ‘single decision-maker’, when it is clear that in the family context ‘the law has had to accommodate forms of participatory or inclusive decision-making which takes at least some account of *all* the legitimate views involved.’<sup>99</sup> Cordell’s role based ethic,<sup>100</sup> discussed in Chapter 1, reveals that the judge brings ‘caring justice’ to the decision-making process. The caring aspect arises as the judge clearly states that s/he is examining the issue through

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<sup>95</sup> Harrington (n12).

<sup>96</sup> McGuinness (n32) 215.

<sup>97</sup> Simon Lee, *Judging Judges* (Faber & Faber 1988) 85.

<sup>98</sup> Fox (n79) 708.

<sup>99</sup> Bainham (n2) 341.

<sup>100</sup> Chapter 1.

a care orientation by making the relationships involved the foci of the investigation of both the medical and familial viewpoints. The overlay of ‘justice’ follows the application of care by utilising the scrutinising function of the Ethics of Care. This facilitates an assessment of the quality and value of the relationships involved and the weight of external influences such as religious belief, societal expectation and resource implications.

Here it is interesting to surmise whether the likelihood of adopting the ‘different voice’<sup>101</sup> of relational reasoning is affected by the gender of the judge. Erika Rackley cautions against gender essentialist claims of all women judges naturally bringing care to the judging process,<sup>102</sup> however, she acknowledges that on an individual level gender could be an influence in conjunction with factors such as race, age and class.<sup>103</sup> Most intriguingly she shares informal accounts of a *collective* influence where the female judge’s assumed ‘particular experience or expertise’ (for instance in relation to motherhood or sex discrimination) is deferred to by her male colleagues and causes the rest of the judicial panel to act differently than they otherwise might have.<sup>104</sup>

### **Section 3 - Relational Reasoning in the Case Law**

Before moving on to the systematic review, it is pertinent to question how convincing relational reasoning is. I will discuss three cases where I argue that relational reasoning has actually been decisive in the outcome of the case. The first two cases

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<sup>101</sup> Chapter 1.

<sup>102</sup> Erika Rackley, *Women, Judging and the Judiciary: From Difference to Diversity* (Routledge 2013) 144.

<sup>103</sup> *ibid* 146.

<sup>104</sup> *ibid* 143.

were heard in 1996, whilst the third occurred in 2002. None of the cases concerned competent children in mid-childhood.

### 3.1 - *Re Y (Mental Patient: Bone Marrow Donation)*(1997)

The first is the case of *Re Y (Mental Patient: Bone Marrow Donation)*,<sup>105</sup> which involved a 25 year-old severely mentally and physically disabled woman, whose sister had a pre-leukaemic bone-marrow disorder and required a bone marrow transplant. Whilst Y was the only potentially compatible donor, she did not have the capacity to understand the nature of the medical procedure. Y's sister sought a declaration under the inherent jurisdiction of the court that blood tests and bone marrow harvesting could be lawfully performed on Y without her consent. Upon first glance it is clear that the proposed procedures could not be shown to be in Y's best *medical* interests, as they were in no way beneficial to her health. However, I would argue the court sought to take a more expansive view of best interests by employing relational reasoning in this case. Evidence of an Ethics of Care approach can be seen by the judge seeking both to place Y in the context of her relationships, and by finding that the proposed interventions were for her 'emotional, psychological and social benefit'.<sup>106</sup>

This is a positive, yet qualified innovation. The court was unwilling to go as far as accepting a purely altruistic justification for the interventions,<sup>107</sup> which Ross has argued may play its part in a full and holistic view of best interests when viewed

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<sup>105</sup> (1997) Fam 110.

<sup>106</sup> *ibid* 116.

<sup>107</sup> *ibid* 113 where Connell J stated that '[t]he fact that such a process would obviously benefit the plaintiff is not relevant unless, as a result of the defendant helping the plaintiff in that way, the best interests of the defendant are served'.

through the lens of care.<sup>108</sup> Yet this may have been a more ‘honest’ reading of the motives underlying the court’s decision. Connell J did make *some* reference to altruism noting the likely benefit to Y’s relationship with both her mother and her sister,<sup>109</sup> however, it may have been a fair assessment to avoid artificially attributing ‘abstract notions of altruism’ to Y,<sup>110</sup> as it was clear that she was unable to understand the needs of others.<sup>111</sup> Elliston applauds the court’s quest for a more concrete motive, founded upon the actual impact of the decision upon Y and her family.<sup>112</sup> However, the resulting reasoning, that if the mother were bereaved as a result of the sister’s death, then she would be less likely to be able to visit Y with negative consequence for Y, appears rather convoluted and tenuous. I agree with Elliston that the judicial reasoning that Y should donate on the basis that ‘her positive relationship with her mother is most likely to be prolonged’,<sup>113</sup> moved emotional best interests beyond a simple cost-benefit exchange between immediate donor and recipient (which would have failed here as there was not a close relationship between Y and her sister) to a consideration of the maintenance of relationships with extended family members.<sup>114</sup> However *Re Y* remains limited in the scope of its relational reasoning, firstly because the medical procedure involved regenerative tissue and the risks associated with intervention were minimal and secondly, the uniquely close nature of the relationship between Y and her mother in the context of her disability may have granted the relationship disproportionate significance in the balancing exercise of the court.

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<sup>108</sup> Freedman Ross (n66) 114.

<sup>109</sup> *Re Y* (n104) 115.

<sup>110</sup> Elliston (n20) 258.

<sup>111</sup> *Re Y* (n104) 112.

<sup>112</sup> Elliston (n20) 258.

<sup>113</sup> *Re Y* (n 104) 115.

<sup>114</sup> Elliston (n20) 253.



### 3.2 - *Re T (A Minor)(Wardship: Medical Treatment)* [1997]

The second case is that of *Re T (A Minor)(Wardship: Medical Treatment)*,<sup>115</sup> which involved C, an 18 month-old baby boy born with a life-threatening biliary atresia whose prognosis was that he would die by 2 ½ without a liver transplant. His parents, who were 'trained healthcare professionals' experienced in caring for sick children, objected to the surgery due to their experience of an earlier failed procedure, which had caused C pain and distress. Additionally, the family had moved to another country that lacked transplant facilities, therefore the child and his mother would need to return to the UK for the duration of the procedure and aftercare. The Local Authority applied for a specific issue order under the inherent jurisdiction of the court, which was granted by Connell J at first instance. The Court of Appeal overturned the judgment at first instance and upheld the parents' appeal.

Again, the courts adopted a relational interpretation of the best interests test, as evidenced by Butler-Sloss LJ 's claim that 'to prolong life (...) is not the sole objective of the court and to require it at the expense of other considerations may not be in a child's best interests'.<sup>116</sup> The case represents a marked departure from the practice of judicial concurrence with medical opinion,<sup>117</sup> with the prime focus resting on the impact upon C's relationship with his mother. Butler-Sloss LJ identified relevant concerns with a relational impact such as the mother's skepticism as to the benefits of the transplant, the dangers of failure, the need for further transplants and the likely length of C's life,<sup>118</sup> but in doing so it may be fair to say that the relational

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<sup>115</sup> [1997] 1 All ER 906, [1997] 1 WLR 242.

<sup>116</sup> *ibid* 916

<sup>117</sup> David Meyers, 'Wyatt and Winston-Jones: Who Decides to Treat or Let Seriously Ill Babies Die?' [2005] Edin LR 307, 311.

<sup>118</sup> *Re T* (n114) 914.

reasoning ‘slips from the best interests of the child (...) to the consequences for the mother’.<sup>119</sup>

A key and apparently decisive influence<sup>120</sup> on the court was the parents’ expertise as carers in the context of the history of care and the future impact of the decision.

However, upon closer inspection the expertise gleaned from the parents’ experience as *parents* was not given much credence, rather, judicial medical deference accorded added weight to the parents’ opinions due to their status as “healthcare professionals”, which may have acted as a shield to prevent any greater scrutiny of the refusal to consent. However, in a fair assessment, Fox and McHale note that the court failed to discern the connection between caring and reasonableness and lamented the extent to which the child’s interests appeared to have been subsumed within those of the mother.<sup>121</sup>

The case has received strong academic criticism as a ‘rogue judgment’,<sup>122</sup> a ‘seriously retrograde decision’<sup>123</sup> and ‘the nadir of the best interests test’.<sup>124</sup> Later jurisprudence appears to have distanced itself from *Re T*’s approach.<sup>125</sup> This is unfortunate, as a prime focus on the child in the context of his relationships, is exactly the starting point advocated by the Ethics of Care. However the judges may have erred, by permitting the medical evidence to be overpowered by relational concerns that were

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<sup>119</sup> Bridgeman (n13) 139.

<sup>120</sup> *Re Y* (n104) 140.

<sup>121</sup> Fox (n79) 705.

<sup>122</sup> Birchley (n2) 284.

<sup>123</sup> Andrew Bainham, ‘Do Babies have Rights?’ [1997] CLJ 48.

<sup>124</sup> M Davies, “Selective Non-Treatment of the Newborn: in Whose Best Interests? In Whose Judgment?” (1998) 49 Northern Ireland Legal Quarterly 82, 93.

<sup>125</sup> See *Re B (A Child) (Immunisation)* [2003] 3 FCR 156 (CA) para 21.

not subject to sufficient scrutiny to justify the weight given to them.<sup>126</sup> A full application of the Ethics of Care would have provided the court with the ability to fully scrutinise the relationships and assess the mother's motives for refusal. This might have revealed the fact that the mother's apparent unwillingness to care for her child post-transplant seemed at odds with the claim that she was a 'loving and devoted mother'.<sup>127</sup> Here, the court needed to clearly establish the worth and meaning of 'care' which, as Fox and McHale advocate, could be a foci for 'rooting the determination of the boundaries of treatment (...)',<sup>128</sup> particularly as her the child's life was at stake.<sup>129</sup>

### 3.3 - *Simms v Simms and an NHS Trust* [2002]

The third case is that of *Simms v Simms and an NHS Trust*,<sup>130</sup> which involved an 18 year-old man, JS and a 16 year-old girl, JA. They were both suffering from variant Creutzfeld-Jakob Disease (vCJD) that rendered them completely dependent and bound to die.<sup>131</sup> There was neither a cure nor a recognized effective drug treatment for the disease, although medical research in Japan had identified a treatment (PPS) whose effectiveness in humans was unknown, as it had only been tested on animals. The parents of JS and JA and the NHS Trust applied for a declaration that the children were incompetent to choose for themselves and that it would in their best interests to receive PPS. The court held, that JS and JA clearly lacked competence and that despite there being an absence of medical consensus in accordance with the *Bolam*

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<sup>126</sup> Kath O'Donell, 'Re C (*Welfare of Child: Immunisation*) – Room to Refuse? Immunisation, Welfare and the Role of Parental Decision-Making' (2004) 16(2) Child and Family Law Quarterly 213, 220.

<sup>127</sup> *Re T* (n114), 909.

<sup>128</sup> Fox (n79) 708.

<sup>129</sup> Hannah Baker, 'MMR: Medicine, Mothers and Rights' (2004) 63(1) Cambridge Law Journal 49, 52.

<sup>130</sup> [2002] EWHC 2734 (Fam)

<sup>131</sup> *ibid*

test on the administration of PPS, given the dire prognosis and the potential benefits, it was in their best interests to receive it.

Although questions of medical innovation and experimental treatment on incompetent patients in the case were significant in the case, Harrington sees key merit in the decision for its relational content, where the ‘practical attitude and wishes of the incompetent patients’ relatives set the parameters of decision-making’.<sup>132</sup> Butler-Sloss P undertook the best interests assessment in the ‘widest possible way’,<sup>133</sup> which Harrington notes caused her to concentrate ‘on the concrete circumstances of both patients’.<sup>134</sup> In particular she weighed up the prospects for each child with and without treatment and the uncertainty and potential burden of treatment. Yet she concluded that their relational circumstances placed them as beneficiaries of ‘devoted and wonderfully caring family’ that meant that the ‘prospect of a slightly longer life’ was worth having.<sup>135</sup> Additionally the court acknowledged the emotional effect upon not only the parents but also the siblings of JS and JA, which would be ‘enormous and palpable’ regarding the loss of opportunity should the declaration be refused.<sup>136</sup> As such Butler-Sloss P gave the views of the families ‘considerable weight’ in the wider best interests assessment.<sup>137</sup>

For Harrington the decisions in *Re Y*, *Re T* and *Simms*, are seen as realizing an Ethics of Care, and the ‘elision of interests’ they reveal is understandable where there is a

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<sup>132</sup> Harrington (n12)

<sup>133</sup> Sims (n129) para 60.

<sup>134</sup> *ibid*

<sup>135</sup> *ibid* para 61.

<sup>136</sup> *ibid* para 64.

<sup>137</sup> *ibid*.

close and caring family.<sup>138</sup> However, he also notes that these cases imply that the worth of the incompetent patient is determined by the ‘willingness and ability of their families to care for them’ and that in the context of indifferent or abusive families the ‘patient is worth less, because they are valued less by their relatives’.<sup>139</sup> Whilst I concur with Harrington that these three cases are encouraging in their demonstration of relational reasoning, I am less pessimistic about the potential negative impact of such reasoning on those without caring families. Although not demonstrated in these cases, a full application of the Ethics of Care along with the scrutinizing function of the overlay of caring justice would protect the individual interests of the child patient. In cases where over-reliance on care appears to produce an unjust result, such as in *Re T*, the Ethics of Care would place the child in his relational context, but caring justice would seek to uncover the motives of the mother in her refusal to consent to the suggested treatment and to counterbalance these with the justice of seeking to protect the individual health needs of her son.

#### **Section 4 - Systematic Case Review 1990 - 2016.**

In this section, I shall analyse the case-law relating to medical treatment for children in mid-childhood in the context of the five criticisms laid out in section 1.1, and with a view to uncovering examples of relational reasoning. This will be done with the proviso that healthcare cases are, and should be, particularist in nature and therefore appreciating the limitations of the exercise, as identified by Waite LJ in *Re T* – ‘All these cases depend on their own facts and render generalisations—tempting though they may be to the legal or social analyst—wholly out of place’.<sup>140</sup> However, I believe

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<sup>138</sup> Harrington (n12) 7

<sup>139</sup> *ibid* 7

<sup>140</sup> *Re T* (n23) 917.

that it *is* useful to attempt to discern trends or patterns in reasoning and the types of arguments that have been fostered or rejected by the courts, in order to be able to more clearly discern the aspects of the application of the best interests test where the Ethics of Care framework would be most useful.

#### 4.1 - Methodology

The time frame used was a period of 26 years, from 1990 - 2016. This was chosen because, as became apparent from an initial manual overview, the relevant cases only started to appear in the jurisprudence from the early 1990s.<sup>141</sup> Further, 26 years represents a significant time period over which to analyze changes or patterns in judicial reasoning. The initial criteria established for the search were cases that involved at least one child who was aged between 8 and 14 years old ('mid-childhood') and where the prime focus of the case was upon medical treatment or healthcare decision-making. Cases where the child fell within the age range but where a mental or developmental disability or condition rendered them as dependent and lacking in capacity as an infant or young child, were excluded.<sup>142</sup> Also cases where healthcare was merely a side issue and the main focus was for instance upon adoption, care proceedings or contact, were likewise excluded.

The search terms sought to identify the topic of healthcare law and the relevant age range and used 'best interests', 'welfare' and 'Children Act' as key words in the search. The search below, was run through the legal databases Lexis Library and

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<sup>141</sup> Although Brazier (n34) notes that the difficult balancing act between medical best interests and parental opinion was 'first essayed' more generally in the case of *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421 (CA).

<sup>142</sup> An example is the case of David Glass - *R v Portsmouth Hospital NHS Trust ex parte Glass* [1999] 2 FLR 1019. Although he fell into the required age range, at 12 years old, was excluded because his profound learning disabilities rendered him wholly dependent.

Westlaw and a simplified version through the databases Family Law Online and BAILLI, and the eJournal Medical Law Reports:

(medical OR "health care") and (child!) and ("best interests" OR welfare) and ("children act") and (age! +2 8 or 9 or 10 or 11 or 12 or 13 or 14) NOT (adoption)

The results showed a total of 10 cases involving children aged between 8 and 14, with the first case appearing in 1993, and the last in 2015.<sup>143</sup> Because of the small number of cases, the search was expanded to include children aged 15 and 16 and this resulted in a further 9 cases which fell between 1990 - 2014, making the total sample 19 cases. Although the latter search fell outside of the initial search criteria, it was hoped that principles or patterns of reasoning might be identified that may be transposed to the younger age range.

#### 4.2 - Facts of the cases

Before moving on to analysis of the cases, I shall outline the facts of each case. In the interests of space, this shall necessarily be brief. Eighteen of the nineteen cases will be analyzed by theme, followed in section 5 by a more detailed analysis of the recent case of *F v F*.<sup>144</sup> This will act as a case study of how the Ethics of Care framework explained in section 1.3 might have been used.

I will begin with two initial observations from the cases. First, that the earlier cases 1-9 dealt with older adolescents (with the exception of case 7, where the child was 14) and were largely concerned with questions of *Gillick* competence and

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<sup>143</sup> One of the cases – *F v F* involved both an 11 and 15 year old girls but because of the presence of the 11 year old, it was included in this category.

<sup>144</sup> [2013] EWHC 2683 (fam).

the impact of s8(1) Family Law Reform Act 1969. Indeed it was not until case 7 in 1998, that the courts were faced with a healthcare case involving a child in mid-childhood.<sup>145</sup> The evidence from the subsequent cases 10-19, suggested that concerns around competence largely fell outside of the questions surrounding mid childhood; until this assumption was undermined by the 2014 case of *An NHS Trust v A, B, C and a Local Authority*,<sup>146</sup> and revisited later that year in *Re JA*.<sup>147</sup> Yet apart from demonstrating the judicial approach to child competence, these earlier cases do shed some light on topics such as the nature of best interests, the weight of medical opinion and the potential for children to participate in decision-making. A second general observation is that in none of the 19 cases reviewed did the courts reach a decision that was contrary to the medical opinion, whether that was to commence or continue treatment, or to cease it, despite the weight of relational concerns or the refusal of consent by the parents or the child.

#### CASE 1 - *Re E* [1990]<sup>148</sup>

A 15 year-old boy was diagnosed with leukaemia. The hospital wished to provide the most effective treatment; involving the administration of 4 drugs and the occasional blood transfusion. Both the boy and his parents refused to consent due to their Jehovah's Witness faith. The Court held that such objections were contrary to the boy's well being and it was in accordance with his welfare that he should be treated.

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<sup>145</sup> *Re L* [1998] 2 FLR 810.

<sup>146</sup> [2014] EWHC 1445 (fam).

<sup>147</sup> *Re JA (A Minor)(Medical Treatment: Child Diagnosed with HIV)* [2014] EWHV 1135 (Fam).

<sup>148</sup> *(A Minor) (Wardship: Medical Treatment)* [1992] 2 FCR 219.



CASE 2 - *Re R* [1991]<sup>149</sup>

A 15 year-old girl in Local Authority care, displayed serious mental health problems and was admitted to a psychiatric unit. The Hospital wished to treat her with anti-psychotic drugs, however the Local Authority revoked its consent, due to its belief that the girl was competent to choose for herself and in accordance with her refusal of treatment. The Court held that she was not competent and that compulsory treatment was in her best interests.

CASE 3 - *Re W* [1993]<sup>150</sup>

A 16 year-old girl in Local Authority care, was diagnosed with anorexia and the LA recognizing that a feature of anorexia was the need for control, applied to the court for a direction that she could be placed in a specialist clinic and treated without her consent, should she refuse. The court held that although the girl was competent, it had the power to override her wishes and order treatment in her best interests.

CASE 4 - *Re K, W and H* [1993]<sup>151</sup>

Three girls aged 15, 15 and 14 were being detained in a specialized secure unit for highly disturbed adolescents. This was due to a diagnosis of Conduct Disorder for the two 15 year olds and Bipolar Effective Disorder for the 14 year old. The Health Authority applied to the courts for Section 8 Specific Issue Orders in relation to treatment in the face of the children's refusal to consent. The court held that a Section 8 order was unnecessary and that the key test was *Gillick* Competence and the parental right to consent in the face of child refusal.

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<sup>149</sup> (*A Minor*) (*Wardship: Consent to Treatment*) [1992] Fam 11, [1991] 4 All ER 177, [1992] 2 FCR 229.

<sup>150</sup> (*A Minor*) (*Medical Treatment*) [1992] 4 All ER 627, [1993] Fam 64.

<sup>151</sup> (*Minors*) (*Medical Treatment*) [1993] 1 FLR 854

CASE 5 - *Re S* [1995]<sup>152</sup>

A 15 year-old girl was suffering from potentially life-threatening Thalassaemia. The girl ceased her hospital treatment regime due to her resentment at the interference, and refused necessary blood transfusions, influenced by the Jehovah's Witness of her mother. The Local Authority applied for a declaration that she should continue with treatment. The court held that the girl was not *Gillick* competent and gave permission for treatment, in her best interests.

CASE 6 - *Re C* [1997]<sup>153</sup>

A 16 year-old girl who was suffering from anorexia, was enrolled in a specialist clinic but refused to comply with treatment and repeatedly absconded. The Local Authority applied for an order permitting compulsory treatment, which the girl opposed. The Court held that although the girl was over 16 it had the power to detain her and order compulsory treatment in her best interests.

CASE 7 - *Re L* [1998]<sup>154</sup>

A 14 year-old girl suffered very serious burns after falling into a hot bath. The hospital wished to perform three surgeries in order to save her life and minimize future scarring. However as blood transfusions were a necessary aspect of these surgeries, the girl and her parents refused to consent due to their Jehovah's Witness faith. The Court held that the girl was not competent and ordered treatment in her best interests.

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<sup>152</sup> (*A Minor*)(*Refusal of Medical Treatment*) [1995] 1 FCR 604.

<sup>153</sup> (*A Minor*)(*Detention for Medical Treatment*) [1997] 3 FCR 49.

<sup>154</sup> (*Medical Treatment: Gillick Competency*) [1998] 2 FLR 810, [1999] 2 FCR 524.

CASE 8 - *Re M* [1999]<sup>155</sup>

A 15 year-old girl was suffering heart failure and the hospital wished to perform the only possible treatment, which was a heart transplant. Her mother consented to the procedure but the girl refused claiming she did not wish to have someone else's heart, nor take medication for the rest of her life but neither did she wish to die. The court held that under the welfare test the risks of her resentment were outweighed by the certainty of death and thereby authorized the transplant.

CASE 9 - *Bromorganwg NHS Trust v 'P' and another* [2003]<sup>156</sup>

A 16 year-old boy was suffering from hypermobility syndrome and a suspected ruptured aorta. He was admitted to hospital where the proposed treatment involved the use of blood products but the boy refused to consent due to his devout Jehovah's Witness faith. The court held that assessing the boy's interests in the widest possible sense, and notwithstanding his faith, his interests would be met by receiving the treatment.

CASE 10 - *Re C & F* [2003]<sup>157</sup>

Two unconnected applications involving two girls aged 4 and 10, whose fathers both wished for their daughters to be immunized. Their mothers opposed it – one for personal reasons and the other due to her “holistic” lifestyle. The court weighing up the medical evidence favouring immunization against the emotional risks to the child's relationships with their mothers and it held that it was in the children's best interests to be vaccinated.

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<sup>155</sup> (*A Child*)(*Medical Treatment*) [1999] All ER (D) 798.

<sup>156</sup> EWHC 2327

<sup>157</sup> (*Children*) [2003] EWHC 1376 (fam).

CASE 11 - *Re S* [2004]<sup>158</sup>

An 8 year-old boy had been raised in both the Jain and Muslim faiths of his parents. His parents separated and his Muslim mother became his primary carer and wished for him to become a practicing Muslim and therefore to be circumcised. His Jain father objected. The boy did not wish to be circumcised. The court held that as circumcision is a permanent procedure and that performing it may have an impact on the boy if he chose Jainism in adulthood, it was not in his best interests.

CASE 12 - *Re A, B, C and D* [2011]<sup>159</sup>

Four children aged 13, 9, 6 and 5 were placed into Local Authority care due to parental neglect and the Local Authority sought a declaration of the court for authorization for the children to receive various vaccinations. The Parents opposed this due to their belief that the MMR caused autism. The court held that on the evidence it was in their best interests to receive the immunisations.

CASE 13 - *F v F* [2013]<sup>160</sup>

Two sisters aged 15 and aged 11 had been raised in a household, which objected to immunization. However after the parents separated the father sought a declaration and Specific Issue Order from the court that both girls should receive the MMR vaccine. The mother maintained her objection to vaccination, as did both girls; although the 15 year-old's refusal was based on her vegan principles. The court held that despite weighing up the girls' views, they were not *Gillick* competent and it was in the girls' best interests to be vaccinated.

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<sup>158</sup> (*Children*)(*Specific Issue Order: Religion: Circumcision*) [2004] EWHC 1282 (fam).

<sup>159</sup> (*Welfare of children: Immunisation*) [2011] EWHC 4033 (Fam)

<sup>160</sup> *F v F* [2013] EWHC 2683 (Fam).

CASE 14 - *An NHS Foundation Trust v A and Others* [2014] <sup>161</sup>

A 15 year-old girl, suffering from persistent vomiting and weighing 5 ½ stone had been in hospital for 10 months. The Trust applied to the court for a declaration that the girl could be fed via a NJ tube, a treatment which neither the girl or her mother would consent to. The court held that the girl was not *Gillick* competent and that by surveying a wide canvas of medical and social issues and giving due weight to the girl's views, it was in her best interests to receive the proposed treatment.

CASE 15 - *An NHS Trust v A, B, C and a Local Authority* [2014] <sup>162</sup>

A 13 year-old girl was found to be 21-weeks pregnant and the NHS Trust sought a declaration as to whether the girl was competent to consent to continue with, or terminate her pregnancy. The position of the NHS Trust was that if she was found to be incompetent it would be in her best interests to have a termination, which concurred with the expressed wishes of the girl herself. The court held that the girl was *Gillick* competent and therefore permitted to make the decision for herself.

CASE 16 - *In the matter of X* [2014] <sup>163</sup>

A 13 year-old girl, who was the subject of ongoing care proceedings, was found to be 14 weeks pregnant by a 14 year-old boy. A declaration was sought as to whether the pregnancy should be terminated. The court held that the fulfillment of the legal criteria for termination under the Abortion Act 1967 was a matter for the doctors and not the court and was indeed a prerequisite to the court ruling on the matter. The girl

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<sup>161</sup> EWHC 920.

<sup>162</sup> *A, B, C* (n145).

<sup>163</sup> (*A Child*) [2014] EWHC 1871

was not *Gillick* competent and her wish to have a termination was decisive in the best interests assessment.

CASE 17 - *Re JA* [2014] <sup>164</sup>

A 14 year-old boy was diagnosed as HIV+ but refused to consent to receiving ART. His parents, who were also HIV+, refused to consent, partly due to their refusal to believe that HIV was a 'proper' medical diagnosis and partly because of suspicion around conventional treatment. The NHS Trust sought a declaration that the child was not *Gillick* Competent to refuse ART. The Court held that due to the child being unable to weigh up information about HIV and treatment, he was not *Gillick* Competent and it was in his best interests to receive treatment.

CASE 18 - *M Children's Hospital NHS Foundation Trust v Mr and Mrs Y* [2014] <sup>165</sup>

A 13 year-old boy suffered sudden and catastrophic ill-health due to post-infectious cranial and spinal demyelination. The treatment offering the best chance of recovery was PEX, which involved the administration of blood products. There was uncertainty around the boy's competence due to his fluctuating consciousness and his mother was unable to consent due to her Jehovah's Witness faith. The Hospital Trust applied to the court for a declaration that it was lawful to administer the treatment. The court held that it was in the boy's best interests to receive the treatment.

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<sup>164</sup> *Re JA (A Minor)(Medical Treatment: Child Diagnosed with HIV)* [2014] EWHV 1135 (Fam).

<sup>165</sup> EWHC 2651

#### CASE 19 - *Re JM* [2015] <sup>166</sup>

A 10-year old boy was suffering from a rare aggressive tumour in his jawbone that needed urgent treatment or the boy would die within 6-12 months. The parents and the boy himself both refused to consent to surgery; the parents preferring Chinese medicine. The court held that the child was not Gillick competent and that it was in his best interests to undergo surgery.

### 4.3 - Case Analyses using the Five Criticisms

#### 4.3.1 - *The Nature of Best Interests*

16 out of 19 cases addressed the issue of the nature or scope of the best interests test, albeit with varying degrees of detail. In the remaining three cases, there was no explicit reference to the nature of the test.<sup>167</sup> The prime focus in the early cases such as *Re E* was the need for a ‘judgment to be taken objectively’ despite ‘compassion’ for the child’s view.<sup>168</sup> Whilst in *Re R* Waite J claimed judicial jurisdiction to make his own assessment as to paramount best interests,<sup>169</sup> recognition of the potential for judicial subjectivity can be detected in the subsequent case of *Re W*. Here Nolan LJ notes that ‘I am very far from asserting any general rule that the court should prefer its own view as to what is in the best interests of the child to those of the child itself’.<sup>170</sup> There is a resistance to acknowledging judicial subjectivity, with judges preferring to cloak their judgments in “objective” language. However there are glimpses of judicial subjective biases in some of the cases, for example in Ward J’s reaction to *E*’s religious beliefs as discussed in 4.4 3 below. Yet this display of

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<sup>166</sup> *Re JM (A Child)* [2015] EWHC 2832 (Fam); [2016] 2 FLR 235.

<sup>167</sup> *Re S (A Minor)(Refusal of Medical Treatment)* [1995] 1 FCR 604. *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810, [1999] 2 FCR 524.

<sup>168</sup> *Re E* (n147)

<sup>169</sup> *Re R* (n148).

<sup>170</sup> *Re W* (n149)

objective reasoning may act to obscure the reality that in some cases the parents or child's subjective viewpoint is being replaced with the subjective viewpoint of the judge, evidenced by the fact that in only one of the 14 cases<sup>171</sup> was the child's view determinative.

The clearest base line for determining best interests is found in *Re W* where Nolan LJ begins from the 'general premise' that it implies at least a protection of life until the child reaches 18 and is free to choose for herself.<sup>172</sup> Whilst this stance appears entirely reasonable, intervention in the name of welfare has been extended beyond survival, as illustrated by Cobb J's statement in *M Children's Hospital* that 'there is a strong presumption that treatments designed to prolong, or enhance quality of life should be attempted'.<sup>173</sup> Such reasoning has even been applied to cases such as immunization, which might deal with merely an entirely theoretical threat to health.

In relation to the specific factors of the welfare checklist, only factor a – the wishes and feeling of the child receives any comprehensive treatment. In *Re W*, Nolan LJ, asserts that the child's wishes and feelings are the *first* factors the court must assess.<sup>174</sup> Donaldson LJ claims that welfare equates with giving the child 'the maximum degree of decision-making',<sup>175</sup> albeit subject to the restraints of 'prudence', which reveals that participatory opportunities declared in theory are again limited by a cautious paternalism in practice. Balcombe LJ appears to equate the potential for meaningful participation with an increase in age,<sup>176</sup> exposing a reliance on the strict

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<sup>171</sup> *ABC* (n145).

<sup>172</sup> *Re W* (n149) 647.

<sup>173</sup> *M Children's Hospital* (n164) para 10.

<sup>174</sup> *Re W* (n149) 647.

<sup>175</sup> *ibid* 638.

<sup>176</sup> *ibid* 642.



developmental model of the child. In contrast, a care approach would render increased participation dependent on more particularist factors such as maturity, insight from experience, desire to participate and the importance of the issue at stake to the child. This latter theme is picked up in the later cases on abortion, such as *X* where Munby S claims that ‘the court must surely attach considerable weight indeed to the albeit qualified autonomy of a mother who in relation to a matter as personal, intimate and sensitive as pregnancy is expressing clear wishes and feelings’.<sup>177</sup> This judicial latitude may be attributed to the lack of clear consensus on what is ‘best’ in the case of proposed termination of pregnancy, unlike other cases where there is usually a clear indication of what is medically ‘best’.

The only other specific welfare criterion that is briefly mentioned is factor b, where in *Re C* Wall J makes reference to the treatment regime being ‘appropriate to C’s needs’.<sup>178</sup> This coupled with Johnson J’s reference to ‘best’ being equated with the doctor’s clinical judgment in *Re M*,<sup>179</sup> exposes a narrow interpretation of the child’s needs, focused largely on the physical and clinical, rather than the expansive relational interpretation advocated under the Ethics of Care. *Re S* [2004] is unique in that Baron J makes *specific* mention of the actual criteria of the welfare checklist, which she asserts she must take into account, and ‘hold each very fully in her mind’.<sup>180</sup> Yet even here she declines to set them out verbatim as they ‘are so well known’ and there is little evidence of their weight or relevance in the judgment

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<sup>177</sup> *X* (n162) para 10.

<sup>178</sup> *Re C* (n152) 59.

<sup>179</sup> *Re M* (n154) 798.

<sup>180</sup> *Re S* (n151) Para 74.

The later cases see the emergence of rights concerns. This accords with a general trend towards greater judicial acceptance of human rights concerns, more so as a result of a cultural shift due to the incorporation of the Human Rights Act 1998, and evidenced in legislative rights safeguards such as found the Mental Capacity Act 2005. In *Re C & F*, Sumner J identifies the tension between the welfare test and rights such as freedom of speech.<sup>181</sup> Yet discussions of rights remain cursory and are inevitably trumped by welfare. This is seen in *Re A, B, C & D* where Theis J rejected a claim of interference with the rights guaranteed by Article 8 ECHR, holding that the order to vaccinate 4 children in the face of parental objection was a necessary interference of their right to family and private life.<sup>182</sup> The current judicial approach is summed up in *Re C & F* where Thorpe LJ asserts that the judge must merely consider ‘all relevant factors’ but that the order of consideration is for him, provided that each is kept in its ‘proper proportion’ and accorded the weight that ‘he deems it deserves’.<sup>183</sup> In sum, the cases reveal that Fox and McHale’s identification of ‘judicial reluctance’ in articulating the nature of best interests holds true, thereby verifying the criticism that the test remains vague and indeterminate.

#### 4.3.2 - Deference to Medical Opinion

As would be expected, all of the cases made some reference to the medical evidence regarding the proposed treatment. However, judicial deference to medical *opinion* was as *not* as strongly borne out in the cases as criticism 2 might suggest. Inevitably when a series of assessments deemed there was a “need” to prevent ‘irreparable

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<sup>181</sup> *Re C & F* (n156) para 298

<sup>182</sup> *Re A, B, C & D* (n158) Para 17.

<sup>183</sup> *Re C & F (Children)* [2003] EWHC 1376 (fam), On Appeal - *B (A Child)* [2003] EWCA Civ 1148, para 24.

damage to [the child's] health and risk to her life',<sup>184</sup> the courts invariably held that the treatment should proceed regardless of the weight of the child's objection. In *Re W* Lord Donaldson states that a change in circumstances rendering W's situation an emergency, resulted in her objections being 'completely outweighed' by the necessity of medical treatment.

In *Re E* Ward J's use of the medical evidence is subtler as he uses the evidence of the 'infinitesimal' risk associated with blood transfusion to bolster his equation of best, with the opportunity to live a 'precious life'.<sup>185</sup> Yet, surely the interest in preserving a 'precious life' stemmed not merely from the medical ability to keep E alive but the relational interest in the continuation of the bonds between the child and his family. Ward J's justification for intervention on the basis that the medical risk was not one that would have stood in E's father's way 'but for his religious conviction',<sup>186</sup> is a straw man. Neither E nor his parents presented any objection on medical grounds. Their view of E's welfare was framed in religious terms and therefore the riskiness of the procedure was wholly irrelevant.

In some of the cases, the courts *did* reject medical opinion when it failed to comply with the judicial notion of best interests. In *Re R* Waite J supplanted psychiatric evidence that R was competent to refuse, with his view that he was 'very far from satisfied' that the child had 'been free from the constraints which her years impose on the powers of decision'.<sup>187</sup> *Re S [2004]* may be anomalous in its downplaying of the medical evidence as to the relative safety of circumcision in preference for the

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<sup>184</sup> *Re W* (n149) 636.

<sup>185</sup> *Re E* (n147) 226-7.

<sup>186</sup> *ibid*

<sup>187</sup> *Re R* (n148) 237.

weightier matters of religious freedom and social policy. This may be due to the fact that the proposed procedure was not medically *necessary*. In addition there may have been some underlying medical ambivalence, in the vein of Fox and Thomson's contention that circumcision 'has long existed as a procedure in search of a medical rationale'.<sup>188</sup> The more recent cases dealing with younger children show a marked shift, seemingly in line with care thinking, in that medical opinion featured as but one source of information and was often counterbalanced by other views. This may again hark back to the distinction in the judges' minds between life threatening and other cases. These more recent cases were of the latter kind and as they were freed from the shadows of the child's imminent death the courts are prepared to afford greater recognition to importance of relational matters to children in mid-childhood. In *Re S [1995]* Johnson J benefited from hindsight in acknowledging that the outcome in *Re E*- that upon reaching 18 E had refused blood transfusions and subsequently died, pointed to a serious consideration of the 'background of misery' that might result in S's case by forcing her to receive treatment for what might amount to only 2 ½ years more life.<sup>189</sup> The most thorough balancing of medical and relational concerns is seen in the case of *Re C & F* where Sumner J carefully weighed the 'clear and persuasive' medical evidence in favour of immunization against the great importance of the impact on the mothers care of their daughters, although ultimately relational concerns did not outweigh the medical necessity.<sup>190</sup>

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<sup>188</sup> Marie Fox and Michael Thomson, 'Older Minors and Circumcision: Questioning the Limits of Religious Actions' (2008) 9(4) Medical Law International 283, 294.

<sup>189</sup> *Re S* (n151) 614.

<sup>190</sup> *Re C & F* (n156) para 343.

However in the case of *ABC*<sup>191</sup> we see a re-emergence of medical deference used as a legitimizing force. Three times in the mere 18 paragraph judgment Mostyn J claims that his attempts to summarise the seemingly straightforward psychiatric evidence would ‘not do justice to [its] clarity’,<sup>192</sup> ‘may lead to its full impact being lost’<sup>193</sup> and was done ‘probably inadequately’,<sup>194</sup> to the extent that he deemed it necessary to attach the transcript of the Dr’s evidence to the judgment. Here judicial incertitude generated a complete reliance by the judge upon the psychiatric evidence in his determination of A’s competence. Writing elsewhere on this case, I note that it is possible to see this not as a matter of deference in the traditional sense of an unquestioning reliance upon medical opinion,<sup>195</sup> but rather a respect for the expertise of the medical professional. Yet, whilst it is true that Mostyn J did clearly acknowledge that Dr Ganguly was a ‘consultant psychiatrist of some considerable experience’,<sup>196</sup> it is questionable how far a simple assessment of capacity is a matter of medical expertise.<sup>197</sup> Furthermore, Mostyn J’s reliance is out of step with a more recent trend, as identified by Muireann Quigley, for deference to medical opinion to be supplanted by a form of deference to *judicial* opinion on issues such as capacity and best interests.<sup>198</sup> What in fact may be at the root of this ‘deference’ is a regrettable but somewhat understandable process of mutual legitimization.<sup>199</sup> Underlying the judgment is the suspicion that the case was bought as a result of fear on the part of clinicians about negative public reaction, although ultimately no such reaction was

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<sup>191</sup> *ABC* (n145).

<sup>192</sup> *ibid* para 11

<sup>193</sup> *ibid* para 12

<sup>194</sup> *ibid* para 15.

<sup>195</sup> Moreton K, ‘Gillick Reinstated: Judging Mid-Childhood Competence in Healthcare Law: *An NHS Trust v ABC & A Local Authority* [2014] EWHC 1445 (fam)’ [2015] 23(2) Medical Law Review 303, 310-11.

<sup>196</sup> *ABC* (n145) para 11.

<sup>197</sup> Moreton (n195) 310-11.

<sup>198</sup> See Muireann Quigley, ‘Best Interests, the Power of the Medical Profession and the Power of the Judiciary’ (2008) 16 Health Care Anal 233.

<sup>199</sup> Moreton (n196) 311.

evident in media reporting of the case.<sup>200</sup> This is a reversion to the provision of the judicial ‘flakjacket’ posited by Lord Donaldson in *Re W*,<sup>201</sup> where law is being used by doctors as a means of reinforcing their judgments.<sup>202</sup>

#### 4.3.3 - Judicial Paternalism v The Child’s Participation

All but one of the cases,<sup>203</sup> made reference to the wishes of the child, the extent of their participation, or the weight accorded to their views. Particularly in the cases involving older adolescents there were strong statements, such as from Johnson J in *Re S* [1995] that ‘I start unhesitatingly from the position that S’s wish should be given effect unless the balance is strongly to the contrary effect’.<sup>204</sup> Furthermore, the courts appear to be aware of the implications of overriding a child’s wishes with Mostyn J in *Re JM* stating that ‘I give full weight to the wishes of J (...) It is a strong thing for me as a stranger, to disagree with and override the wishes of J (...)’<sup>205</sup> and Hayden J in *A and Others* noting that ‘I have ...given very considerable weight to her strongly expressed resistance’.<sup>206</sup>

The early cases attempted to tackle the question of *Gillick* competence but in all of them either the seemingly competent child was found to lack competence or more controversially, children whose competence was acknowledged had their wishes overridden in their best interests. Brazier and Bridge claim that the reasoning supports the judgments in cases where the child was clearly mentally disturbed or traumatised

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<sup>200</sup> See Shoba Rao, news.co.au (10 May 2014). The headline was later changed to ‘Thirteen year old girl gets legal right to decide to have an abortion for the High Court in London’; Suespicious Minds, ‘Thirteen year old has the capacity to terminate pregnancy’ (12 May 2014) <[suespiciousminds.com/2014/05/page/2/](http://suespiciousminds.com/2014/05/page/2/)> <Last accessed 16 July 2014>.

<sup>201</sup> *Re W* (n149) 785.

<sup>202</sup> Bainham (n3) 342.

<sup>203</sup> *Re A, B, C & D* (n158).

<sup>204</sup> *Re S* (n151) 614.

<sup>205</sup> *Re JM* (n165) para 15.

<sup>206</sup> *A and others* (n160) para 15.

by abuse.<sup>207</sup> For example, in *Re R*, the child was deemed to be incompetent to her lack of stability, as Lord Donaldson noted that ‘extent of competence does not fluctuate day to day or week to week’.<sup>208</sup> Whilst in *Re W*, the child’s attitude that ‘she was in control and could cure herself if and when she thought it right to do so’ was a consequence of her anorexia which rendered her incompetent as she lacked the understanding that she ‘might leave it too late’.<sup>209</sup>

However, despite the statement of Waite J in *Re R* that ‘the fact that a jurisdiction is paternal does not entitle the court to be paternalistic’<sup>210</sup> the reasoning and outcome of the cases reveal an overarching paternalism towards all the children concerned. This is most pressing in the cases where the child’s life was in danger, with Ward J summing up the judicial dilemma with the question ‘is this choice of death one which a Judge in wardship can find to be consistent with the welfare of the child?’<sup>211</sup>

Whilst the desire to preserve life in these circumstances is clearly understandable, it is also in these cases that the child’s reasons for refusal tend to be the most sincere and closely related to the child’s sense of self. Refusals in circumstances where the child is not suffering any mental disorder but rather the refusal of consent is founded on religious grounds present the most difficult dilemmas.<sup>212</sup> As seen in the Jehovah’s Witness cases they require the courts to decide ‘whether to allow the child (...) to put faith before life’.<sup>213</sup> They present the tension between the child beliefs – which on one

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<sup>207</sup> Margaret Brazier and Caroline Bridge, ‘Coercion or Caring: Analyzing Adolescent Autonomy’ (1996) 16 (1) Legal Studies 84, 103

<sup>208</sup> *Re R* (n148) 246.

<sup>209</sup> *Re W* (n149) 637.

<sup>210</sup> *Re R* (n148) 236.

<sup>211</sup> *Re E* (n147) 226.

<sup>212</sup> Brazier (n206) 89.

<sup>213</sup> *ibid* 103.

hand were variously described as ‘devoted and strongly devout’,<sup>214</sup> of ‘integrity and commitment’<sup>215</sup> and ‘a very large part of her life,’<sup>216</sup> on the other the judicial attitudes that such beliefs are ‘irrational’<sup>217</sup> and cause one to be ‘almost baffled’.<sup>218</sup> This is reminiscent of Fox’s and McHale’s querying of the legitimacy of the downplaying of religious belief in *Re T*<sup>219</sup> and reveals a judicial inability to accept that some beliefs may be more precious to believers even than life itself. The children’s faith appears to have been both “dangerised” and infantilised in order to justify paternalistic intervention. In *Re S* [1995] the child’s “childish” hopes for a miracle were used as evidence of her incompetence.<sup>220</sup> In *Re E*, Ward J presents religious faith as both a source of danger by asserting the adversarial stance identified by Bridgeman - that E needed to be protected from himself and his parents,<sup>221</sup> and downgrades E’s religious beliefs to ‘embarrassing’ convictions professed in ‘callow youth’ that may diminish with time.<sup>222</sup> I agree with Burns that relegating faith to the status of a teenage fad is ‘effectively driving a coach and horses through the *Gillick* competent child principle’<sup>223</sup> and accords insufficient respect and weight to beliefs that run right to the core of the child’s identity.

Of course, there *are* legitimate concerns around allowing children’s wishes to be determinative when death may be the outcome. In such circumstances many would concur with Margaret Sommerville’s assertion of the inherent wrong in breaching the

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<sup>214</sup> *Re E* (n147) 221.

<sup>215</sup> *Re S* (n151) 616.

<sup>216</sup> *Re L* (n153) 527.

<sup>217</sup> *Re W* (n149) Lord Donaldson 637.

<sup>218</sup> *Re E* (n147) 226.

<sup>219</sup> Fox (n79) 702.

<sup>220</sup> *Re S* (n151) Johnson J 616.

<sup>221</sup> *Re E* (n147) 227.

<sup>222</sup> *ibid* 226.

<sup>223</sup> Seamus Burns, ‘Bad Blood’ (2007) 157(7300) *New Law Journal* 1722,1725.



key societal value of special respect for human life.<sup>224</sup> However, in a case such as *Re E* where the child was clearly competent and his refusal was based on long-held beliefs that were core to his sense of self, it is apparent that in acting upon the ‘intuitive response that there is something desperately wrong in a child dying’<sup>225</sup> a wrong is done to Sommerville’s second inherent value- that of serious harm to the “human spirit”.<sup>226</sup> She coins the term ‘dis-valuation’ to describe the discounting of the less visible or less understandable ‘emotional and spiritual suffering’,<sup>227</sup> such as suffered by E and his family when refusals are overridden. In this case I concur with Brazier and Bridge’s worst-case outcome that the judicial intervention ‘simply prolonged his waiting for death’.<sup>228</sup> It is my view that in a case such as E’s his views and those of his family should have been determinative.

Yet, it was not until the recent case of *ABC*<sup>229</sup> that the *Gillick* took centre stage. Mostyn J declared that ‘the question of best interests does not really inform the primary decision I have to make which is whether she has the necessary capacity’.<sup>230</sup> It is the first mid-childhood case that has found both the child to be *Gillick* competent and permitted her wishes to be determinative. It is striking in that the child involved was only 1 week past her 13<sup>th</sup> birthday and Mostyn J’s judgment perhaps marks a return to the application of the test for competence as it was initially framed in *Gillick*. Such an interpretation may have been aided by the apparent consensus between the child, the hospital and the judge that the termination was in accordance

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<sup>224</sup> Alfred Aman et al, ‘The Ethical Canary: Science, Society and the Human Spirit – by Margaret Sommerville’ (2002) 9(2) *Indiana Journal of Global Legal Studies* 555, 562.

<sup>225</sup> Margaret Sommerville in Aman (n215) 575.

<sup>226</sup> *ibid*

<sup>227</sup> Margaret Sommerville, *The Ethical Canary: Science, Society and the Human Spirit* (Penguin Books 2004) 196.

<sup>228</sup> Brazier (n206) 104.

<sup>229</sup> [2014] EWHC 1445 (fam).

<sup>230</sup> *ibid* para 10.

with A's best interests. However Mostyn J's dicta that a competent child's wishes were determinate, 'even if the result of that would lead her to take steps which are wholly contrary to her best interests',<sup>231</sup> stands in stark contrast to the judicial caution exhibited in the earlier cases involving older adolescents, discussed above. Furthermore the fact that the court permitted her to choose for herself a matter as serious as abortion raises new questions around the courts judgment just a year before that a seemingly competent 15 year-old was too naïve to refuse the MMR vaccination.<sup>232</sup>

For the majority of cases where the child was deemed not to be *Gillick* competent, the extent of the child's participation in the decision-making process became relevant. Justifications for maximizing this participation included recognising that older adolescents are nearing the point of adult freedom of choice,<sup>233</sup> plus an implicit judicial attentiveness to the child's interest in bodily integrity.<sup>234</sup> On the latter point, Fox and Thomson lament the courts' preference for the 'impoverished' 'Blackstonian' property model of bodily integrity.<sup>235</sup> They offer a reformulated concept of *embodied* integrity to inform best interests assessments, which is able in a more nuanced way to capture the relationality and materiality of children's bodies, which has much in common with aspects of Guideline One of my Ethics of Care framework developed in Chapter 2.<sup>236</sup> The courts however often eschewed such subtleties. In many cases increasing participation was granted in correlation with increasing biological age, which is understandable given that it is a definite criterion

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<sup>231</sup> *ibid* para 10.

<sup>232</sup> *F v F* (n143).

<sup>233</sup> *ibid*

<sup>234</sup> *Re S* (n157) 616.

<sup>235</sup> Marie Fox & Michael Thomson, 'Interrogating Bodily Integrity' [2014] (Forthcoming) 27.

<sup>236</sup> *ibid* 4.

for judges to engage with.<sup>237</sup> Yet Lord Donaldson in both *Re R*<sup>238</sup> and *Re W* preferred the less arbitrary measures of increased experience, intelligence and understanding<sup>239</sup> and encouragingly, in *Re C & F* Sumner J recognised that even a 10 year old was ‘old enough’ to express views about her treatment.<sup>240</sup> However, it is rare within the cases to actually hear the child’s *words*. In the four cases where we do, two reveal powerful statements about the strength of the child’s views<sup>241</sup> and the psychological and social implications of the decision. In *Re S [1995]* the 15 year old girl expresses that an enforced blood transfusion would ‘be like a rape’ because ‘[h]aving someone else’s blood is having someone else’s soul’,<sup>242</sup> whilst the 15 year-old in *Re M* declares that ‘I would rather die than have the transplant (...) I would feel different with someone else’s heart, that’s a good enough reason not to have a heart transplant, even if it saved my life’.<sup>243</sup>

The minimizing of the child’s capacity to understand or accept information in order to protect them from “harmful” information is further evidence of paternalism. Such an assertion of incompetence becomes self-fulfilling as a result of the very withholding of the information necessary to facilitate informed choice. In *Re E*, it was deemed problematic to probe E about his understanding of how frightening his death may

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<sup>237</sup> Fox (n187) 292.

<sup>238</sup> *Re R* (n148) 246.

<sup>239</sup> *Re W* (n149) 638.

<sup>240</sup> *Re C & F* (n156) paras 311 & 346.

<sup>241</sup> In the third case where we actually read the child’s words - *Re S* [2004], the 8 year olds response to whether he wished to be circumcised was that he did not, as his father had told him that it meant that his ‘willy would be chopped off’.<sup>241</sup> This response was used as evidence of his incapacity to understand. Although presumably this could have been remedied with accurate information, it may also indicate the limitations to the potential for participation. Likewise in the fourth case *Re JM*, the 10 year-old boy declared he did not wish to have reconstructive surgery on his jaw using skin and bone from his leg as he did not ‘want to have a foot in my mouth’ (para 8).

<sup>242</sup> *Re S* (n151) 607, 612.

<sup>243</sup> *Re M* (n154).

be<sup>244</sup> and in *Re L*, the ‘very grave’ details of the manner of death which faced her, was not information ‘appropriate’ to reveal.<sup>245</sup> Her ‘sheltered’ upbringing was used to indicate her limited her understanding of matters as grave as her own situation. This is clearly a value judgment by the court on the characteristics of ‘maturity’, the test for which Sommerville posits as ‘how autonomous, independent, self-determined and individualistic that person is’.<sup>246</sup> Yet it hard to fathom how *any* person, aged 14 or not, would have been sufficiently prepared in such sudden accidental circumstances. Indeed the ‘sensible disciplines’<sup>247</sup> of her faith and upbringing probably fitted her better for the task than most. In *Re R Waite J* adopted a more nuanced stance by acknowledging that whilst the ‘sheer force of immaturity’ might act to undermine the child’s decision-making capacity, there clearly lurks in many adults ‘ (...) a Peter Pan who surfaces at times to mock the status of maturity’ whilst many children exhibit a wisdom beyond their years’.<sup>248</sup> However, in practice we see judicial caution, which confirms the criticism made of *Gillick* discussed in Chapter 2, that by setting the bar beyond which a child’s wishes would be determinative so high that it is likely that no child could ever reach it.

Further, the courts reject the kind of collaborative decision-making that would be advocated by the Ethics of Care as a means of enhancing the capacity of children in mid-childhood. In *Re E*, Ward J set the child’s refusal in the context of his love and respect for his parents and ‘the conditioning effect of the very powerful expressions of his faith’ in order to determine that E’s views were not ‘the product of his full and his

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<sup>244</sup> *Re E* (n147) 224.

<sup>245</sup> *Re L* (n153) 526.

<sup>246</sup> Sommerville (n226)192.

<sup>247</sup> *ibid* 527.

<sup>248</sup> *Re R* (n148) 236.

free informed thought'.<sup>249</sup> This illustrates an atomistic interpretation of decision-making and a suspicion that collaborative decision-making is tainted by undue influence. Brazier and Bridge contend that E was subject to 'influence of the strongest kind' including 'a life-long indoctrination bolstered by the convictions of his parents and church elders', which they surmise left 'little room (...) to exercise free will'.<sup>250</sup> However, within the Ethics of Care the wish for parental love and need to maintain familial religious integrity would be a natural and desirable part of living in relation and not a *prima facie* indication of lack of competence. Indeed, surely the purpose of religious faith is that it acts as a strong guiding, and in some instances constraining, influence in any believer's life and therefore an adult may be no more 'free' in this respect than a child. The fact is that adults and children alike are influenced, and choose to be so influenced in their decision-making, by any number of ideologies, responsibilities and social conventions. To pretend otherwise is to revert to the myth of autonomy, as discussed by Fineman.<sup>251</sup> To acknowledge this then begs the question why is adherence to religious influences particularly singled out as likely to undermine free will?

#### 4.3.4 - Relational Reasoning

In 16 out of the 19 cases was there reference to concerns that could broadly be categorized as relational.<sup>252</sup> Even then, consideration of impact of the decision upon the child's relationships was generally piecemeal and secondary to other factors, and in no case did relational reasoning play the role that it had in *Re Y*, *Re T* or *Simms* as discussed in Section 3 above. In relation to the discussion in section 2.3 as regards the

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<sup>249</sup> *Re E* (n147) 226.

<sup>250</sup> Brazier (n206)104.

<sup>251</sup> Martha Fineman - see Chapter 1.

<sup>252</sup> There was no mention of relational reasoning in *Re R* [1992], *Re C* [1997], *Re A, B, C & D* [2011]

gender of the judge, there appears to be no clear correlation between cases who are heard by women judges and those that contain relational reasoning. However it does appear that the earlier cases heard by Butler-Sloss LJ and the later ones by Baron J and Theis J, generally give greater prominence to care and relationships than many of the other cases.

At the most basic level, some of the cases drew attention to the implications of the decision for the *child* personally in the context of her relationships. In *Re W*, the court concluded that the ‘quasi-family bonding’ that W experienced at the specialist clinic was a relevant consideration in making the order to compel her to remain there,<sup>253</sup> whilst in *Re E*, Ward J considered the distress that E would suffer as ‘a loving son’, helplessly watching his family’s distress.<sup>254</sup> Yet, here there is a skewing of relational concerns, as Ward J makes use of E’s upset at a recount of his father’s love for him, as evidence of his incompetence to decide. ‘Upset’ in the face of death and the prospect of being separated from loved ones, should not be deemed as a sign of childish immaturity, but rather reveals the importance of relationality that we would all feel in such circumstances. Indeed, as noted in Chapter 1, Fineman<sup>255</sup> argues that vulnerability is an essential trait of the *human* condition, and surely fear of death would be an obvious manifestation of this.

In other cases, the courts were prepared to go further with relational reasoning in brief referring to the impact of the decision on connected *others*, yet these ideas remained largely undeveloped. In *Re W* Donaldson LJ noted W’s Aunt’s concern for the effect

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<sup>253</sup> *Re W* (n149) 639.

<sup>254</sup> *Re E* (n147) 224.

<sup>255</sup> Martha Fineman, ‘The Vulnerable Subject and The Responsive State’ [2010] 60 Emory law Journal 251.

of the publicity of the case upon W's younger brother.<sup>256</sup> More interestingly the court in *Re L* gave relevance to the care given by healthcare staff as they considered the impact of their 'distressing task' of attending L as she died a 'horrible death'.<sup>257</sup> In *Re JM*, Mostyn J lamented lack of parental cooperation with the healthcare professionals and the courts, and was alert to the fact that 'the collaboration of the parents with the proposed surgery is essential'.<sup>258</sup> This impact of lack of parental cooperation on the well-being of the child was identified in *A and Others*, where Hayden J opined the mother's resistance as 'rather troubling' and concluded that her behavior indicated a 'dysfunctional understanding of her daughters needs, physically and emotionally'.<sup>259</sup> In *Re C & F* relational concerns played a larger part as the court sought to determine the respective weights of the mothers' versus the fathers' views regarding their daughters vaccinations. In particular, some weight was accorded to the emotional effect on the mothers of imposing procedures on their daughters against their wishes, which they claimed would be 'unduly distressing',<sup>260</sup> 'very threatening',<sup>261</sup> and in the case of C's mother 'strikes at the heart of who she is'.<sup>262</sup> Yet judicial caution in validating only some types of relational reasoning appears to lie in the distinction between those views which are "non-threatening" to the child's welfare and which the courts can readily understand and sympathise, and those which appear to be self-serving or hint at influence which may act to undermine the traditional child-centred view of best interests.

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<sup>256</sup> *ibid* 631.

<sup>257</sup> *Re L* (n153) 526.

<sup>258</sup> *RE JM* (n165) para 12.

<sup>259</sup> *A and Others* (n160) para 30 and 32.

<sup>260</sup> *Re C & F* (n156) para 20.

<sup>261</sup> *ibid* para 227.

<sup>262</sup> *ibid* para 242.

On a third level, two cases assessed the relational importance of the child's connections within their religious community. In *Re L*, Sir Stephen Brown was encouraged by the fact that the Jehovah's Witness community would continue to support L if blood transfusions were administered. In contrast, Baron J in *Re S* [2004] refuted the mother's claim that she and her children would be rejected by the Muslim Community if her son was not circumcised and felt the potential of rejection held insufficient weight as she retained her family support and social contacts.<sup>263</sup> Most promisingly from a care perspective, is the evidence in two cases of the success of the scrutinizing function of the Ethics of Care that acts to look beyond the face value of a relationship in order to discern its true strengths or failings. In *Re S* [1995] Johnson J's reference to reports of S's mother's claim that she would rather that S had died,<sup>264</sup> the 'puzzling' home atmosphere and the lack of gestures or words of affection from the mother,<sup>265</sup> presumably fed into the weight he accorded to the her views. Further a close examination of the parents relationship with each other and their children in *Re S* [2004] lead to the conclusion that the mother's 'dissembling' and the father's discreditable behaviour,<sup>266</sup> exposed that maternal professions of care were merely a cover for a desire to perpetrate a deception of devout religiosity that the court was not prepared to sanction.

#### 4.3.5 - Shortsightedness – Inattention to past caring practice or future impact

Criticism Five was not wholly borne out as 16 out of 19 cases made some attempt to consider either past care or the future implications of the decision.<sup>267</sup> However, judicial desire was often thwarted by evidential shortcomings, as illustrated by

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<sup>263</sup> *Re S* (n157) Para 83

<sup>264</sup> *Re S* (n157) 612.

<sup>265</sup> *ibid* 613.

<sup>266</sup> *Re S* (n157)

<sup>267</sup> It was not mentioned at all in *Re W* [1992] or *Re C* [1997].



Farquarharson LJ's refusal in *Re R* to assess the child's capacity at the present moment only, 'isolated from medical history and background',<sup>268</sup> or Johnson J's lamentation in *Re S [1995]*, of 'one-sided' evidence due to a lack of information about the stance of the Jehovah's Witness community.<sup>269</sup>

Past care and future impact appeared to hold less sway in cases where the child's life was at stake, again highlighting the apparent distinction between the types of cases where the courts might be more amenable to care reasoning. In *Re E* however, Ward J did consider the potential future emotional trauma that E might experience after a coercive blood transfusion but deemed it did not outweigh the emotional trauma of pain, and fear of dying.<sup>270</sup> This evaluation may have been better balanced however, if the past care from E's family and religious community had also been considered. Such may have revealed that the emotional trauma from receiving the transfusion may have been more significant than Ward J supposed whereas the dying process may have been viewed as inevitable and relatively short-lived in comparison.

Under an Ethics of Care, the purpose of assessing past caring practices would be to evaluate the weight accorded to the opinions of the carers. This was graphically illustrated in *Re A, B, C & D* where Theis J noted that although despite careful consideration of parental views, on this occasion they should be 'weighed in the light of an almost complete failure by the parents to cooperate with health professionals and a neglect of the children's health'.<sup>271</sup> The most poignant example of judicial consideration of the future impact of the decision is found in *Re M*, where Johnson J

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<sup>268</sup> *Re R* (n148) 251.

<sup>269</sup> *Re S* (n151) 607.

<sup>270</sup> *Re E* (n147) 227.

<sup>271</sup> *Re A, B C & D* (n158) Para 17.

wrangles with the risk that M may bear life-long resentment for what is done and that upon receiving the heart transplant she ‘will live with the consequence of my decision, in a very striking sense’.<sup>272</sup> Yet, caution and scientific veracity win out as he concludes that the unknown emotional risk cannot outweigh the certainty of death.<sup>273</sup>

It is in *Re C & F* that we see the most successful example of placing the decision in a longer-term context, which in many ways equates with the approach advocated by care thinking. Sumner J begins with the claim that a good reason why a declaration might not be made is if ‘it would so affect the mother that her ability to care for the child would be impaired (...)’.<sup>274</sup> First the court turned to a history of caring practice, recognizing the importance of the bond between the child and the primary carer and its duty to safeguard and preserve that bond.<sup>275</sup> Sumner J then weighed the benefits of the proposed treatment against the potential damage to the relationship and the importance of care, drawing in the future implications of requiring a mother to care for a child after a procedure to which she is opposed.<sup>276</sup> Finally the mother’s ability to cope with and accept the decision is assessed and ultimately found not to prevail when the best interests of the child in every other sense point to receiving the vaccination.

### **Section 5 - *F v F*: A Contemporary Case-Study**

In this final section I shall use a recent healthcare case<sup>277</sup> involving children in mid-childhood as a contemporary case study. I will examine the presence of relational

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<sup>272</sup> *Re M* (n154).

<sup>273</sup> *ibid*

<sup>274</sup> *Re C & F* (n156) Para 5.

<sup>275</sup> *ibid* Para 316.

<sup>276</sup> *ibid* Paras 317 & 318.

<sup>277</sup> *F v F* (n143).

thinking and assess how applying the Ethics of Care framework may have changed the outcome, or at least the decision-making process. The case is a fitting study, in that it involves two children in the (extended) defined age bracket, which enables a comparison to be made about the treatment of each. Further, as it does not involve questions of life and death, it is not subject to the attendant pressures and time constraints of such cases and so allows for more nuanced decision-making. Finally, it is one of the rare cases where the children's reasoning is actually documented in the judgment.

### 5.1 - The Facts

The case concerned two sisters L, aged 15 and M, aged 11. L had been vaccinated as an infant but had not received her boosters, whilst M had received no vaccinations. This was due to parental concerns in the wake of the MMR controversy.<sup>278</sup> After the parents separated, the mother became the primary carer. The father grew concerned that his daughters were not vaccinated, which increased following the discrediting of the MMR study and an outbreak of measles in Wales. The mother maintained her objection to vaccination and both girls also refused to consent. The father applied to the court for a declaration and a specific issue order.<sup>279</sup> Theis J held that despite carefully weighing up the girl's views against vaccination that they had been shaped by a number of factors that affected their weight, and ultimately rendered the girls incompetent to decide. As the medical evidence 'pointed all one way',<sup>280</sup> it was in the girls' best interests to be vaccinated and therefore the declaration was granted.

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<sup>278</sup> This relates to the 1998 Paper authored by Dr Andrew Wakefield that claimed that the MMR Vaccination was linked to autism and bowel disease.

<sup>279</sup> Children Act 1989 s8.

<sup>280</sup> *F v F* (n143) Para 16.

## 5.2 - Viewing the Case through the Lens of the Ethics of Care

In many ways the case is progressive, in that some of the relevant factors under the welfare checklist were more clearly articulated than in previous cases. In addition both the wishes of the girls and the relational aspects of the case featured heavily. However by applying the Care Framework discussed in section 1.3, certain gaps and controversies become apparent.

### 5.2.1 - Attentiveness to the Individual Interconnected Child in her Particular

#### Circumstances

The first, and perhaps most important failing in the case is that the interests of the two girls were treated together. Theis J relied on the evidence from the caseworker that the girls should not be treated differently<sup>281</sup> and L's views were dismissed as 'naïve' despite an acknowledgement that she was better informed and had greater understanding than M.<sup>282</sup> Theis J noted that she found the girls to be 'intelligent, articulate and thoughtful'<sup>283</sup> – traits which might indicate competence, yet there was no investigation as to whether either of the girls were *Gillick* competent.<sup>284</sup> Rather, Theis J clearly stated that she would be applying the welfare principle.<sup>285</sup> Presumably any consideration of the children's wishes was then a matter of weight rather than decisiveness.

In contrast, the first guideline of the Ethics of Care framework draws attention to the importance of treating each child as an *individual* and considering her particular

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<sup>281</sup> *ibid* Para 15.

<sup>282</sup> *ibid* para 22 (2).

<sup>283</sup> *ibid* Para 6.

<sup>284</sup> Marcia Persaud, 'F v F: latest Developments in Children and Consent to Medical Treatment' (4 November 2013) The Barristers' Hub <<http://www.barristershub.co.uk/archives/practice-areas/family>> <Accessed 13 March 2014>.

<sup>285</sup> *F v F* (n143) Para 8.

vulnerability, embodied experience and concrete circumstances. This could utilize welfare criteria such as age, sex and background and physical, emotional and educational needs as well as the child's wishes.<sup>286</sup> It is clear that L's case *was* markedly different to M's. Addressing L first, at 15 she was presumably physically and emotionally more mature than her 11 year-old sister. Her objection was principled, being based upon her veganism, which precluded her from partaking of the animal-based ingredients in the MMR.<sup>287</sup> Further, her claim that she would be 'upset if it were in her body',<sup>288</sup> goes directly to her embodied experience of being compelled to receive the MMR. Emma Cave notes that the court underplayed the significance of coerced treatment in the face of continued refusal by the girls, both on a practical level in finding a doctor willing to participate and in relation to their bodily integrity as she suggests that coercive medical procedures are 'one of the most serious invasions (...) sanctionable in a democratic society'.

The court discounted L's views as unbalanced and immature and much was made of the fact that she had not thought through the implications should she need to take medication upon becoming ill as a result of not being vaccinated. Yet Cave exposes the fallacy of this assessment when she reveals that there is no treatment for measles, mumps or rubella.<sup>289</sup> I concur with Herring here that 'many people hold strong moral principles' and that as such there was no need for her to consider the "wider picture" because the principle should dictate what should happen'.<sup>290</sup> Conversely, many principled people will take time and care to adhere to those principles in every day

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<sup>286</sup> Children Act 1989 S1(3)(a)(b)(d).

<sup>287</sup> *F v F* (n143) Para 10 (4).

<sup>288</sup> *ibid* para 13.

<sup>289</sup> Emma Cave, 'Adolescent Refusal of MMR Inoculation: *F (Mother) v F (Father)* [2013] EWHC 2683 (Fam) [2014] 77(4) Modern Law Review 630.

<sup>290</sup> Jonathan Herring, 'An Injection of Sense' [8 November 2013] New Law Journal 9.

life where they have the luxury of choice but may have to make some compromises in an emergency situation. For L adhering to her vegan principles may have been more important to her at this point in time than the potential risks from not being vaccinated. In addition L's mother gave evidence of her psychological problems with anxiety,<sup>291</sup> which may have rendered the impact of a coerced procedure more onerous for L than for M. Finally L's medical position *was* different from that of M, in that she had received her initial vaccinations, which offered her at least 90% immunity.<sup>292</sup> As Cave rightly notes the question should have been decided by examining L and M's particular medical positions and the risks of them being unvaccinated for the next 3 or 7 years respectively, until they reached adulthood and could choose for themselves. Yet, this point was wholly ignored in the case, in preference for a generalistic view of the medical evidence and aligned with NHS public health agenda that the MMR vaccine was safe and effective.<sup>293</sup>

We have far less information about 11 year-old M, who in many ways is overlooked in both the judgment and the academic commentary. Because the interests of the two girls were conflated,<sup>294</sup> in certain respects M's competence is obscured. On one hand the father's claim that M was strongly influenced by her sister<sup>295</sup> may have resulted in attributing her sister's principled refusal to her, when she may have held no such views. On the other, M's bewilderment as to her father's change of mind was used as evidence of immaturity, which may have been unfairly attributed to L also. Under the

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<sup>291</sup> *F v F* (n143) para 10(3).

<sup>292</sup> For the 10% of children who are not immune after the first vaccination, the booster merely reduces that figure to 1%. See David Hunter, 'Court decision to force MMR wasn't in child's best interests' (19 November 2013) *The Conversation* <<https://theconversation.com/court-decision-to-force-mmr-in-childs-best-interest-20383>>

<sup>293</sup> Cave (n288) 3, 6-7.

<sup>294</sup> *ibid*

<sup>295</sup> *F v F* (n143) para 12.

Ethics of Care the paternal-daughter relationship would have been more closely scrutinized to assess the veracity of the father's claim that the girls 'think he is trying to exert control on the mother and using them as a vehicle to do this'.<sup>296</sup> There was no evidence of psychological problems for M, but emotionally she may have been more dependent upon her mother than L and thus the caseworker's observation that she wished to 'align herself with the views of her mother and sister',<sup>297</sup> without forming her own view, may have been fair.

### 5.2.2 - Consideration of the Child's Past and Future Caring Relationships

There are two key points to note here. First, that Theis J deemed that neither girl's views would hold much weight as they were skewed by a lack of balanced information and the strong influence of the mother. Given that earlier in the judgment she had noted that the girls asked questions that were 'perceptive',<sup>298</sup> an Ethics of Care approach would seek to maximize their capacity to participate meaningfully by facilitating the provision of the necessary accurate information,<sup>299</sup> *before* a decision about their competence was made.<sup>300</sup> Theis J drew attention to the mother's statement that 'the girls will feel they have let her down'.<sup>301</sup> Yet viewed through a care perspective 'there would be something odd' if the girls were not naturally influenced by their mother.<sup>302</sup> Equally it could be claimed that their father influenced them if they favoured vaccination. Within the Ethics of Care the 'empathy' that the girls showed for their parents,<sup>303</sup> would be translated into an understanding of the responsibilities

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<sup>296</sup> *ibid.*

<sup>297</sup> *ibid* Para 19.

<sup>298</sup> *ibid* para 6.

<sup>299</sup> Hunter (n291).

<sup>300</sup> Cave (n288) 10.

<sup>301</sup> *F v F* (n143) para 11.

<sup>302</sup> Herring (n289) 9.

<sup>303</sup> *F v F* (n143) Para 15.

they bore to each other and their mother, as a consequence of living in relation. However, influence in and of itself does not indicate that they were unable to form views for themselves.<sup>304</sup> It may have been that Theis J gave more weight to this point because the mother's views were the less orthodox, at least medically, of the two parents and thus it fitted the finding of best interests to discredit her influence.

### 5.2.3 - Evaluation of the Social Context of Care

The social context of care draws attention to the medical evidence and the societal expectations regarding vaccination. There was very little discussion about the medical benefits, and adherence to a policy agenda was not expressly discussed,<sup>305</sup> although as noted above, it seems to underlie the rationale for the decision. Under an Ethics of Care approach it is imperative that each decision should be made on a particularist basis. However, policy considerations should be an important part of the assessment under Guideline Three both in terms of placing the girls' decision into its wider social context and also as a mechanism to temper the potential injustice of particularist decision-making. Therefore the responsibility on the girls as citizens - to consider the impact on others of them failing to be immunized, would be a consideration along with any possible social stigma they may face for failing to contribute to the "herd immunity".

There was the contention that the girls' views were formed on the basis of a negative focus, which is hardly surprising considering that they were not in favour of the vaccination, and as Cave contends, had they expressed views both for and against the

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<sup>304</sup> Herring (n289) 10.

<sup>305</sup> Cave (n288) 3.



procedure they may have been dismissed as being undecided.<sup>306</sup> A care framework would draw upon the welfare criteria as to the likely effect on each child of a change of circumstances.<sup>307</sup> This would lend added weight to the mother's evidence that both girls had 'grown up in a frame of mind which they were settled in and supported in the same outlook and are now forced to take a different view (...)'<sup>308</sup> and would focus attention upon the preservation of future relationships with her as the prime carer. Theis J touched on this, asserting her confidence that the parents would ensure that the consequences of the court's decision were managed responsibly. Yet care's scrutinising function might reveal the irony of the judicial removal of the ability of the parents to exercise their responsibility in this matter; that function having been claimed by the court in determining the Specific Issue, only then to invoke that same parental responsibility to deal with the consequences of the judicial decision. Additionally, it might expose the fact that as the parents had previously been unable to agree, to the extent that the issue had come to court, such confidence might be misplaced.

In sum, by applying the Ethics of Care it appears that the outcome of this case may have been different, at least for L. Although the fact that she appeared to be *Gillick* competent should have been sufficient to enable her to make her own decision, as demonstrated in the earlier cases the courts are often very willing to override the wishes of even the competent child with whom they disagree. Plus as argued throughout this thesis, it is in the wider relational concerns revealed through care, of which competence is but *one* aspect, that the most holistic portrayal of the child's life

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<sup>306</sup> *ibid* 11.

<sup>307</sup> Children Act 1989 S1(3)(c).

<sup>308</sup> *F v F* (n143) Para 11.

is revealed. In addition, factors such as that the procedure in question was not treatment but rather merely preventive healthcare;<sup>309</sup> L's principled reasons for refusal; the potential damage to her emotional well-being and the need to maintain the relationship with her mother; all suggest she should have been able to choose for herself not to be vaccinated. For M, the absence of individual assessment and lack of discussion of the risks to her emotionally or relationally, mean there is insufficient information to make the same pronouncement. Given that the medical risks were also greater for her it may be that it *was* in her best interests to receive the vaccination.

### **Concluding Thoughts**

In conclusion, this chapter has demonstrated that despite its flaws, the best interests test is the pragmatic choice when determining questions of children's healthcare in mid-childhood. In addition, I have demonstrated that it is capable of modification to take account of relational interests. It has been established that the task of judging is a complex and subjective one but that judges should be clearer in their articulation of the factors of the welfare checklist and the weight that they accord them. 'Just caring' can be utilized to bring balance to all viewpoints within a particular case. The systematic review found that not all of the five criticisms were consistently borne out. The earlier cases tended to demonstrate more paternalistic reasoning and provided less scope for the child's participation but later cases have shown more progress. The claim of medical deference was not as strong as first posited and I would concur with Quigley<sup>310</sup> that the shift has been away from a medical deference to a judicial one. Yet the most recent case of *F v F* shows that paternalistic instincts remain strong and that

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<sup>309</sup> Hunter (n291).

<sup>310</sup> Quigley (n11).

even in cases involving relatively minor healthcare issues, the courts have never been prepared to allow the child's views to be determinative. Yet, the case study also demonstrated that the Ethics of Care framework *can* be successfully applied to healthcare cases in mid childhood and that it acts both as a descriptive ethic of some elements of the judgment and as a normative framework to highlight the factors that should be of relational importance. The result is that not only is the decision-making process different but potentially the outcome also.

## **PART TWO – THE CASE STUDIES**

Part Two of this thesis encompasses Chapters 4 - 6 and marks a shift in focus away from theoretical and doctrinal legal analysis, towards a more practical application of the Ethics of Care framework which was advocated in Part One. Each of these subsequent chapters will take the form of a case-study that will focus on one scenario that holds particular resonance with the challenges posed by mid-childhood healthcare decision-making, as discussed in Chapter 2. They include accommodating the child's views and expertise, conceptualizing the child in the context of her relationships, and the impact on the child's identity of social mores, religious doctrine and public policy. To these ends, Chapter 4 will consider end of life decision-making, Chapter 5 will examine living organ donation by children and Chapter 6 will explore treatment protocols for transgender children.

These chapters venture into new territory largely uncharted by law – in each area there is a complete absence of directly relevant UK case law, yet each poses dilemmas that could potentially result in litigation. In light of this absence I have chosen to explore the topics by way of case study, and the purpose of adopting this approach here is threefold. First, as discussed in the introduction, this format provides a single context-rich story or narrative for each scenario. Upon this narrative I will hang an analysis of the value of adopting the care orientation that I advocated in Chapter 1. Further, within the context of these particularist settings, I will assess the importance of the values that I claimed were intertwined with the concept of care, such as trust, vulnerability, and embodiment. Crucially, the format also provides an opportunity to demonstrate how the three guidelines of the Ethics of Care framework, as developed

in Chapter 2, might translate from theory into practice. Secondly, the case studies provide a vehicle to assess how the law might respond to these issues *were* they to come before the courts. As was revealed in the systematic review of the case law in Chapter 3, the key theme from the courts appears to be preservation of life and protection of the child from immature decision-making that could limit their freedom of choice in adulthood. Therefore a notable purpose of the case studies will be to question whether this largely paternalistic and welfare-focused judicial stance would be transposed to these scenarios, or alternatively whether the application of the Ethics of Care framework might open up space for more creative and responsive decision-making than the law has traditionally permitted. Thirdly, by moving beyond a strict application of the law, these case studies provide scope to consider how the Ethics of Care framework might interact with professional guidelines and its impact on wider ethical and policy implications of mid-childhood decision-making.

A final, noteworthy aspect of my approach to the case study model is that although the full Ethics of Care framework will be applied to each scenario, the topic of each study has been carefully selected in order to emphasise, and highlight, the impact and implications in particular of *one* of the three guidelines. Chapter 4's focus on end-of life care was chosen because, perhaps more than in any other area of healthcare decision-making, attention in professional guidance and practice appears to be concentrated on the needs and wishes of the particular patient in a very holistic sense. This neatly reflects the emphasis on particularist and individualized decision-making advocated under Guideline One. Chapter 5's exploration of living organ donation will bring to the fore questions of altruistic motivation, and determination of best interests in cases where there is no medical benefit to the donor child. This will be addressed

by honing in on Guideline Two, to commend a relational construction of best interests as the way forward. Finally, Chapter 6's examination of a new treatment protocol for transgender children gives rise to questions relating to social expectations of children, the potential impact on decision-making of culture and the wider implications for public policy and resource allocation. These issues are aptly addressed by focusing on Guideline Three, to consider questions of justice, the value of social identity and the scrutinizing function within the framework, which can be used to uncover the 'dark side' of care.

**CHAPTER 4**

**END OF LIFE DECISION-MAKING IN MID-**

**CHILDHOOD**

**CASE STUDY ONE**

*‘While always heartbreaking, the most intimate and peaceful (...) deaths are where the [child] trusts their choices are respected, believe that they made a footprint on others’ lives, and are assured that they will be remembered. It is then that they can find meaning in the dying experience and the strength to say good-bye’.<sup>1</sup>*

**Introduction**

On a personal level, the death of a child is one of the most traumatic events that a parent must ever have to deal with. In the developed world child mortality has fallen to such an extent that child death is viewed as utterly upsetting the “natural order” of things.<sup>2</sup> Social taboos that deem discussion of child death to be too emotional or distasteful leave us ‘poorly prepared’<sup>3</sup> for decision-making, by creating barriers to the provision of information, fostering a sense of “otherness” and thereby social isolation

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<sup>1</sup> Lori Wiener et al, ‘When Silence is Not Golden: Engaging Adolescents and Young Adults in Discussions Around End-of-Life Choices’ [2013] 60 *Pediatr Blood Cancer* 715.

<sup>2</sup> A Goldman, ‘An Overview of Paediatric Palliative Care’ (2007) 16 *Medical Principles in Practice* 46.

<sup>3</sup> Daniel Kelly and Jacqueline Edwards, ‘Palliative Care for Adolescents and Young Adults’ in Christina Faull et al (eds), *Handbook of Palliative Care* (2<sup>nd</sup> edn, Blackwell Publishing 2005) 318.

in the dying child, and adding to the overall distress of an already traumatic situation.<sup>4</sup>

These taboos appear to be rooted in the social construction of childhood that was explored in Chapter 1 - Diduck's 'romantic developmentalism';<sup>5</sup> which is an understanding of childhood in both legal discourse and social policy that creates a vision of carefree innocence and a time of preparation for the possibilities of adult life. Accordingly, as demonstrated in the systematic case review in Chapter 3, the general imperative of the law in the context of child healthcare, is not only to preserve life but often to protect the opportunity for choice in pursuit of the child's right to an 'open future'.<sup>6</sup> Yet, this traditional legal model appears to be wholly at odds with decision-making in the face of death. When there is no life to preserve and no future to protect, the assumptions underlying concepts such as for instance, *Gillick* competence, parental responsibility and best interests may be completely disrupted.

According to the charity *Together for Short Lives*, it is estimated that 49, 000 children in the UK are living with conditions that may necessitate them making decisions about end-of-life care.<sup>7</sup> This is especially pertinent in the context of mid-childhood, as improved treatments delay the onset of the symptoms of chronic progressive conditions until later in childhood than they would have been manifest in the past.<sup>8</sup> An empirical study by Hinds et al into the choices of paediatric cancer patients,<sup>9</sup> suggests that decision-making at the end-of-life appears to be freed from the usual

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<sup>4</sup> Together for Short Lives website —< [www.togetherforshortlives.org.uk/about/who\\_we\\_are](http://www.togetherforshortlives.org.uk/about/who_we_are) > <accessed 16 December 2014>

<sup>5</sup> Alison Diduck, *Law's Families* (LexisNexis Butterworths 2003) 79.

<sup>6</sup> Joel Feinberg, 'The Child's Right to an Open Future' in W Aiken and H LaFollette (eds) *Whose Child?* (Littlefield, Adams & Co 1980).

<sup>7</sup> A UK Charity representing children with life threatening and life limiting conditions. Together for Short Lives website (n4).

<sup>8</sup> Joint Working Party on Palliative Care for Adolescents and Young Adults, *Palliative Care for Young People Aged 13-24* (September 2001) 19.

<sup>9</sup> Pamela Hinds et al, 'End-of-Life Care Preferences of Pediatric Patients with Cancer (2005) 23(36) *Journal of Clinical Oncology* 9146



paternalistic constraints that downplay children's present capabilities and minimize the impact of their "voice" in favour of the views of adult decision-makers – a trend identified in the systematic review in Chapter 3.<sup>10</sup> Their claim that the decision-making process they observed 'is at odds with the reported inability of pediatric patients and their parents to influence treatment decisions' seen in other contexts,<sup>11</sup> is contrary to the usual prohibition on a child's refusal of medically beneficial treatment.<sup>12</sup> Thus end-of-life care presents a fitting topic for a case study to examine whether decision-making processes differ in a context where the usual tensions of the mid-childhood triadic are disturbed. To this end I will question whether within this setting law and practice are better able to accommodate a more particularist and holistic form of decision-making, or indeed whether the pervasive 'romantic developmental'<sup>13</sup> view of the child still persists.

This case study will be centred on the story of 12-year old Hannah Jones, who in 2008 chose to refuse a life-saving heart transplant.<sup>14</sup> The first hand account of Hannah's story as encapsulated in the book written by her and her mother Kirsty - *Hannah's Choice: A Daughter's Love for Life: The Mother who let her Make the Hardest Decision of All*,<sup>15</sup> was chosen as it provides an in-depth narrative and context to a rare and controversial example of mid-childhood refusal of life-saving treatment. Such stories reveal the kind of particularized experiences that find their "truth" in personal interpretations of self and identity, intimate connections with family and links with

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<sup>10</sup> Chapter 3, 176

<sup>11</sup> Hinds (n9) 9153.

<sup>12</sup> Chapter 3, 179

<sup>13</sup> Diduck (n5).

<sup>14</sup> Hannah Jones & Kirsty Jones, *Hannah's Choice: A Daughter's Love for Life. The Mother who let her Make the Hardest Decision of All* (London, HarperCollins 2010).

<sup>15</sup> *ibid*

the wider world.<sup>16</sup> Additionally, narrative has a normative function in exposing how such interpretations are and should be the product of the kind of relational, social, cultural and religious influences that rest at the heart of the Ethics of Care, as espoused in Chapter 2.<sup>17</sup> Narrative can be especially useful for capturing the “voices” of those who have been traditionally marginalized.<sup>18</sup> In particular, the accounts relating both to the decision itself and those surrounding the life of the family in the 8 years prior to it, are an especially valuable source for analysis, in that the reader is able to hear the perspectives of the 12 year-old child and mature mother, in all their complex concurrence and conflict.

In applying the Ethics of Care framework to Hannah’s narrative I will demonstrate how ‘Hannah’s Choice’<sup>19</sup> might be justified, and in a more general sense will seek to provide theoretical coherence to what is already happening in good end-of-life decision-making. An additional layer of normative analysis will consider how the Ethics of Care framework might reveal the types of issues that *should* be addressed in end-of-life cases such as Hannah’s. The three stages of the Ethics of Care framework will form the structure for this analysis with particular emphasis in this case study placed on Guideline One. I will consider the implications of a finding of competence or incompetence upon specific areas of decision-making that may give rise to legal or ethical questions, such as child participation; provision of information; advance decisions; and the construction of best interests. Whilst the evaluation will draw on best practice in professional guidance, which at the end-of-life particularly focuses on

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<sup>16</sup> See for example, David Frost, ‘Stigma and Intimacy in Same Sex Relationships: A Narrative Approach’ (2011) 25(1) Journal of Family Psychology 1.

<sup>17</sup> Chapter 2, 116-124.

<sup>18</sup> Jewel Amoah, ‘Narrative: The Road to Black Feminist Theory’ (2013) 12(1) Berkeley Journal of Gender, Law and Justice, 84, 85.

<sup>19</sup> This was a prevailing theme throughout the narrative of Hannah’s story as told in the book authored by her and her mother – that the decision must be Hannah’s choice.

the holistic patient,<sup>20</sup> this case-study will reinforce my thesis that current mechanisms for healthcare decision-making in mid-childhood are incomplete. To address this, I contend that the Ethics of Care is best placed to reveal how to avoid the problem of children in the ‘transition’ stages falling through the gaps in terms of appropriate provision of care.<sup>21</sup> In particular, its use may act to free up some of the constraints addressed in Chapter 3, such as the problems of an overly atomistic focus, deference to medical opinion, decision-making being held hostage to the pressures of time, and the absence of the relational viewpoint.<sup>22</sup> The adoption of the Ethics of Care framework, with the key theme being the role of trust, will produce both a different decision-making process and potentially a different outcome. This will be achieved by subverting the traditional legal stance that views the child as a future “person” yet appears to focus primarily on the situation captured in the specific moment in time presented before the court.<sup>23</sup> Instead, it will enable a view of the “present” child with valuable views and needs of her own, yet whose circumstances are more intimately enmeshed in relationships which are the result of past care and that will bear the future consequences of the decision. Indeed, it will reveal the scope for the kind of creative and particularist legal and medical decision-making that should be fostered to give appropriate weight to the things that seem to matter, even to children, most at the end of life - having a voice, the value of close relationships and the need to be remembered.<sup>24</sup>

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<sup>20</sup> See for example- Royal College of Paediatrics and Child Health, *Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice* (2015); General Medical Council, *0-18 Years: Guidance for All Doctors* (October 2007).

<sup>21</sup> Children and Young People Health Outcomes Strategy, *Final Report of the Children and Young People’s Health Outcomes Forum* (July 2012) 56.

<sup>22</sup> Chapter 3, 138-143.

<sup>23</sup> Chapter 3, 143.

<sup>24</sup> See the quote at the beginning of this chapter from Wiener (n1).

## **What is End of Life Decision-Making?**

### **Section 1 - Defining “Dying”, and Identifying the types of Care at the End-of-Life.**

Diagnosing when a child is dying is notoriously difficult and a ‘far more imprecise science than people recognise’.<sup>25</sup> Yet the impact of such knowledge upon the child and family is profound, as parents report that end-of-life decisions are the most difficult decisions they face during the course of a child’s illness.<sup>26</sup> There are two main scenarios where end of life decision-making in mid-childhood might be necessary. The first is in cases of acute illness, such as Meningococcal infection, or sudden injury following, for example, an accident or act of violence. Here decision-making will often be undertaken in an emergency and will largely focus on whether to withdraw treatment or life support. The second involves children living with chronic conditions, such as cancer, organ failure, cystic fibrosis, HIV or brain and spinal cord injuries.<sup>27</sup> With chronic conditions the deterioration in health may be more gradual, and there may be greater scope for a variety of decisions and increased room for more nuanced and considered decision-making.

One of the key issues in end-of-life care for children with chronic conditions involves the legal and ethical implications that flow from the decision to transition from active treatment to palliative care, and the nature and extent of any palliative care that is to be offered. The World Health Organisation (WHO) describes palliative care as:

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<sup>25</sup> Julia Neuberger, *More Care, Less Pathway: A Review of the Liverpool Care Pathway* (2013 Independent Review of the Liverpool Care Pathway) 19.

<sup>26</sup> Hinds (n9) 9146.

<sup>27</sup> Max Watson et al, *Oxford Handbook of Palliative Care* (2<sup>nd</sup> edn, OUP 2009) 530.

an approach that improves the quality of life of patients *and their families* facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, *physical, psychosocial and spiritual.*"<sup>28</sup>

It is evident that palliative care, by definition, involves the kind of relational care that is advocated by the Ethics of Care. Indeed, *Together for Short Lives* frames the goals in its 3 – year strategic plan in terms of what every *family* should have.<sup>29</sup>

The issues surrounding the diagnosis of dying and the decision to provide only palliative care were acutely brought to light in 2013 in the wake of the Liverpool Care Pathway (LCP) controversy. Whilst there is no evidence that children were placed on the LCP, in order to understand the difficulties in determining appropriate end-of-life care as it might relate to mid-childhood, it is useful to first examine how these might play out in “easier” cases eg: those dealing with adults. The LCP was an integrated pathway of good practice designed for the care of dying adults,<sup>30</sup> which was heavily criticized by the media<sup>31</sup> and in a governmental report,<sup>32</sup> for a multitude of reasons connected with its poor implementation. For our purposes, the pertinent criticism of the LCP was the fear on the part of patients’ families that a ‘diagnosis of death’ was

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<sup>28</sup> *WHO Definition of Palliative Care*, World Health Organisation, <[www.who.int/cancer/palliative/definition/en](http://www.who.int/cancer/palliative/definition/en)> <Accessed 10 November 2014> (emphasis added).

<sup>29</sup> Together for Short Lives website (n4).

<sup>30</sup> John Ellershaw, *Statement regarding LCP Review Publications* (Liverpool, Marie Curie Palliative Care Institute, 2013) 3. <[www.mcpcil.org.uk](http://www.mcpcil.org.uk)> <Accessed 13 December 2014>

<sup>31</sup> Martin William, ‘Liverpool Care Pathway for Dying Patients to be Scrapped after Review’ *The Guardian* (13 July 2013); Tom Rawstorne, ‘My Diary of Mum’s Awful Death on the Liverpool Care Pathway: Nurse’s Heart-Rending account of how Doctors decided to put her Mother on ‘Pathway to Death’ *Daily Mail* (20 October 2012); Max Pemberton, ‘Liverpool Care Pathway: Back to the Old days of Patients Dying in Agony’ *The Telegraph* (3 November 2013).

<sup>32</sup> Neuberger (n25).

prematurely made,<sup>33</sup> and that patients were thereby being inevitably hastened towards death.<sup>34</sup> The *Neuberger Report* into the LCP observed that institutional constraints,<sup>35</sup> professional reticence and a lack of training in discussing death,<sup>36</sup> and an undervaluing of the importance of social and spiritual preferences,<sup>37</sup> precluded the implementation of the holistic type of care that many clinicians themselves claimed they would wish to receive at the end of life.<sup>38</sup>

On an optimistic reading it may be the case that children's palliative care has succeeded where the LCP failed, in avoiding routine application of protocol in a 'tick box' manner,<sup>39</sup> but in practice at least in the adult context, it appears that such individualized care has been difficult to achieve. In paediatric palliative care, WHO recognizes that children require a special and distinct approach,<sup>40</sup> which offers 'the active total care of the child's body, mind and spirit' and stresses the duty of health providers to 'evaluate and alleviate a child's physical, psychological and social distress'.<sup>41</sup> Being more closely aligned with the aims of the Ethics of Care this approach should, in theory at least, help to assuage the kinds of fears expressed by the family members of those on the LCP. This is affirmed by guidance issued by the Royal College of Paediatrics and Child Health (RCPCH), which frames 'optimal ethical decision-making' as requiring 'open and timely communication' with the child and family in the context of 'respecting their values and beliefs'.<sup>42</sup> Yet, the resource implications in terms of time, costs and skill of operating within the confines of the

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<sup>33</sup> *ibid* 20.

<sup>34</sup> *ibid* 29.

<sup>35</sup> *ibid* 40.

<sup>36</sup> *ibid* 44.

<sup>37</sup> *ibid*

<sup>38</sup> *ibid* 3.

<sup>39</sup> *ibid* 3-4.

<sup>40</sup> WHO (n28).

<sup>41</sup> *ibid*

<sup>42</sup> RCPCH (n20) 17.

NHS may still be a constraining factor. I contend that the adoption of the Ethics of Care framework would mean that for the more complex cases in mid-childhood, the possibility of implementing an approach that discerns and responds to the needs of a body experiencing puberty, a mind beginning to develop the capacity for independent thought and a spirit still discovering its beliefs and values, may be more easily facilitated.

## **Section 2 - Relevance to Mid-Childhood**

As noted in the introduction, timing plays a crucial role in the need for end-of-life care arising in mid-childhood. The Joint Working Party report highlighted that improved treatments for chronic progressive conditions mean that these conditions now reach their crisis point later in childhood and adolescence.<sup>43</sup> Consequently, such children have a greater need for palliative care than either younger children or adults under 65.<sup>44</sup> However, law and policy have not necessarily kept pace with the implications of these medical advances; with the prevailing approach throughout much of paediatric healthcare being to treat all under 18s as ‘children’ in the same way. Promisingly however, and in line with the key objective of this thesis to advocate for more particularist decision-making in mid-childhood, treating children as one homogenous group has been criticized in the *Children and Young People’s Health Outcome Forum* Final Report, which asserts that ‘using a single measure for 0–19 year olds is inappropriate’.<sup>45</sup>

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<sup>43</sup> Joint Working Party (n8) 19.

<sup>44</sup> *ibid*

<sup>45</sup> CYPHOS (n21).

In response, the Forum Report proposes that data about children should be presented in 5-year bands, including one that covers the mid-childhood age range of 10-14 years.<sup>46</sup> Although the parameters are slightly different from those used for my framework, this is an approach that I endorse. By way of justification, the Report states that ‘although these feel like narrow bands, *these are times of significant and rapid change in children’s lives and development*’<sup>47</sup> - again tying in with the key theme identified in Chapter 2 of mid-childhood being a period of ‘change’.<sup>48</sup> The analysis in the Report of what these changes might be, also accords with the discussion in Chapter 2, by revealing that ‘development continues in physical, emotional, social and cognitive spheres’,<sup>49</sup> with the key marker of quality of life being an ‘expectation of independence’.<sup>50</sup> Although this marries with the developmental aims of “normal” children, it is important to note that for children suffering from acute illnesses or progressive physical or intellectual impairment, such development may be stymied. This results in the ability to compare oneself with peers being hindered, the need for privacy being compromised, and the child’s sense of autonomy being undermined.<sup>51</sup> Along these lines, Kelly and Edwards draw attention to the fundamental impact of the ‘place of medical technologies on an already changing body’ and the embarrassment that may be caused to the child by, for example, having to expose their body for medical examinations.<sup>52</sup> In sum, this creates complex psychological needs unique to the position of children confronted with the prospect of their own death, as observed by Hannah Jones’ mother Kirsty:

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<sup>46</sup> *ibid* 26.

<sup>47</sup> *ibid* 56 (emphasis added).

<sup>48</sup> Chapter 2, 82.

<sup>49</sup> Joint working party (n8) 8.

<sup>50</sup> *ibid*

<sup>51</sup> Kelly (n3) 321.

<sup>52</sup> *ibid* 322.



She was too weak to do anything other than retreat into herself, but her silence told me everything I needed to know. This was supposed to be her time now- time to go to school and make friends, time to make mistakes and be a teenager, time to grow into her world and create a new one for herself as she moved towards adulthood.<sup>53</sup>

These needs arise from the tension between the desire to reach developmental milestones, whilst experiencing ‘social isolation and becom[ing] increasingly dependent as a result of their illness and impending death’.<sup>54</sup> The implication of this predicament upon the process of decision-making will be examined in the sections below.

## **Applying the Ethics of Care Framework to the Hannah Jones Case**

### **Section 3 - Hannah’s Story**

In 2008 the case of 13 year-old Hannah Jones, hit the headlines.<sup>55</sup> In December 1999, 4 year-old Hannah had been diagnosed with leukaemia, which was treated with chemotherapy. After the first round of chemotherapy, a rare side effect of the treatment developed and Hannah was left with cardiomyopathy. Although her cancer was then in remission, Hannah was only able to receive two out of the proposed six rounds of chemotherapy but lived for the next eight years with a damaged heart.

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<sup>53</sup> Jones (n14) 195.

<sup>54</sup> Joint Working Party (n8) 22.

<sup>55</sup> Shelia McClean, ‘Hannah’s Choice’ *The Guardian* (11 November 2008); Jenny Percival and Paul Lewis, ‘Teenager who Won Right to Die: ‘I have had too much Trauma’ *The Guardian* (11 November 2008); Patrick Barkham ‘Hannah’s Choice’ *The Guardian* (12 November 2008).

At the age of 12 Hannah collapsed, suffering sudden and acute heart failure, plus liver and kidney failure. She was kept alive with the drug Dobutamine, but the doctors suggested that a heart transplant might be her best option. As the procedure was very risky and there were fears that the anti-rejection drugs might cause a reoccurrence of her leukaemia, Hannah refused to consent. However, she did agree to have a pacemaker fitted, as it was a less invasive procedure with an easier post-operative recovery period. The operation was not without complications and, having being given 3-6 months to live, Hannah transitioned to palliative care. After enduring six operations in the previous two years and with a heart that worked at only 10% capacity, she decided that she had had 'too much trauma associated with hospital'.<sup>56</sup> She wished to come off the Dobutamine and return home to die surrounded by her parents and siblings. Her parents supported her decision. The hospital authorities threatened legal action against Hannah's parents if they did not return her to the hospital. However, when a child protection nurse visited Hannah at home to collect evidence for the legal proceedings, she was quickly convinced that Hannah was competent to refuse treatment. The Court action was abandoned and Hannah survived, albeit with seriously diminished heart capacity. The case provoked controversy when it broke in the media almost a year later, with Hannah's parents being accused of child neglect.<sup>57</sup> Further, it produced a fierce debate over whether a child of 12 had the competence to make a decision that would lead to her death.<sup>58</sup>

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<sup>56</sup> Percival (n55).

<sup>57</sup> Emily Retter, 'Hannah Jones at 18: I turned down a heart transplant aged 13 but I'm so glad I changed my mind' *The Mirror* (13 July 2013).

<sup>58</sup> See Comments to Article – McClean (n56) (11 November 2008) *The Guardian*.<  
<http://www.theguardian.com/commentisfree/2008/nov/11/health-ethics?commentpage=1>>; Barkham (n56)

In the event, 18 months after her initial refusal and one week before her 14<sup>th</sup> birthday, Hannah again suffered heart failure but this time underwent successful transplant surgery.<sup>59</sup> Although Hannah's situation differs from scenarios where palliative care is the only option; in that there was a potential treatment for her condition, the case reveals the 'stark picture of the tensions that can sometimes arise at the end-of-life'.<sup>60</sup> In the sections that follow, I will analyse Hannah's story with reference to the decision-making processes and experiences that led her and her mother to make the decisions they did.

## **Section 4 - Applying Guideline One: Attentiveness to the Interconnected Individual Child in her Particular Circumstances - Was Hannah Gillick Competent?**

### **4.1 - Hannah's Participation and Expertise**

*I wanted them to understand that Hannah knew her own mind after so many years of ill health, which is why I trusted her to make this decision (...). Hannah had taught me to have the courage of my convictions and it was only now as it was tested beyond concrete reason into innate faith that I realized this.*<sup>61</sup>

The key legal and ethical question in Hannah's case was if, and how at the age of 12, she was *Gillick* competent to make a decision that might lead to her death. It appears that Hannah's parents and the medical professionals treating her felt confident that

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<sup>59</sup> Barkham (n56).

<sup>60</sup> *ibid*

<sup>61</sup> Jones (n14) 220 – Kirsty Jones on Hannah's Decision to refuse the transplant.

she was capable of making the decision for herself. Yet, as illustrated by the quote above, the process of coming to such a conclusion was not without angst. Rather, her mother expresses how she had to let go of her desire to protect driven by ‘concrete reason’, and be prepared to step into a new realm of understanding – centred on the unique understanding of her child. Just as Dwyer identified that generally children in mid-childhood may be in possession of traits and insights that adults lack as discussed in Chapter 1,<sup>62</sup> so Kirsty drew upon Hannah’s example of having the ‘courage of her convictions’ in order to conclude that ‘Hannah was not a small child any more, she was too old to cajole into doing something she didn’t want, and she had shown her determination again and again’.<sup>63</sup> Contrast this with the cautious approach demonstrated by the courts. As noted in the systematic case review in Chapter 3,<sup>64</sup> when the decision involves life-saving treatment the court begins from the premise that ‘the choice of death’ is not one that a judge can find consistent with the child’s welfare.<sup>65</sup> This protectionist reasoning has also been carried over into more minor cases where there is only a theoretical threat to health, such as in the case of refusal of immunization.<sup>66</sup> Yet, whilst it must be questionable whether such a judicial stance is tenable in the face of imminent death, in Hannah’s case the courts may have seen the transplant as a viable, life-saving option to which she ought not be competent to refuse.

Professional ‘best practice’ does not cohere with the law here, but adopts a higher ethical standard, with RCPCH guidance suggesting that children should be placed in

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<sup>62</sup> Chapter 1, 93. James Dwyer, *Moral Status and Human Life: The Case for Children’s Superiority* (CUP 2010).

<sup>63</sup> Jones (n14) 221.

<sup>64</sup> Chapter 3, 188.

<sup>65</sup> Chapter 3 226, Ward J in *Re E*.

<sup>66</sup> *F v F* [2013] EWHC 2683 (Fam).

the same position as adults,<sup>67</sup> with a presumption of competence unless a child is obviously incompetent.<sup>68</sup> This stance mirrors Foster & Miola's assertion that it is logical that professional ethics occupy a middle ground above the minimum legal standard.<sup>69</sup> However, I concur with their assessment that the greater the ethical content of a decision, such as was true in Hannah's case, the more weight the view of the law should hold.<sup>70</sup> This is because the decision concerns matters other than those of medical expertise. In this situation the law, whilst 'final arbiter', can and should 'respect and embody both professional ethics and personal morality' in order to reach a coherent decision that does not undermine the more progressive stance permitted under daily professional decision-making.<sup>71</sup> However, the reality is that whilst following such guidance would lead to a conclusion that it *is* ethical to withdraw or withhold life-sustaining treatment if refused by a competent child,<sup>72</sup> as Fovargue and Ost have noted in cases where there is a conflict of views, no *court* has ever allowed a child to refuse treatment and die when their life could otherwise be saved.<sup>73</sup> In recent cases greater judicial attention has been paid to the child's right to participate, but these rulings have not involved life and death decisions.<sup>74</sup> Yet, a child who has struggled with long-term illness and is facing decisions about death is in quite a different position to a child that has followed a 'normal' developmental path. I

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<sup>67</sup> See MCA 2005 s 1(2).

<sup>68</sup> RCPCH (n20) 11.

<sup>69</sup> Charles Foster and Jose Miola, "Whose in Charge?" The Relationship between Medical Law, Medical Ethics and Medical Morality', *Medical Law Review* (2015) 23(4) *Medical Law Review* 505.

<sup>70</sup> *ibid* 7.

<sup>71</sup> *ibid* 20, 21.

<sup>72</sup> RCPCH (n20) 10.

<sup>73</sup> Sara Fovargue and Suzanne Ost, 'Does the Theoretical Framework change the Legal End-Result for Mature Minors refusing Medical Treatment or Creating Self-Generated Pornography?' (2013) 13(1) *Medical Law International* 6.

<sup>74</sup> *Re C & F (Children)* [2003] EWHC 1376 (fam); *Re S (Children)(Specific Issue Order: Religion: Circumcision)* [2004] EWHC 1282 (fam); *An NHS Trust v A, B, C and a Local Authority* [2014] EWHC 1445 (fam).

contend that factors specific to the position of these children should carry additional weight when deciding whether the child has reached the *Gillick* threshold.

An underlying explanation for the confidence in Hannah's competence may be that those in relationships closest to her were enabled to adopt this higher ethical standard, by applying the kinds of considerations found under Guideline One. They were able to view Hannah as individual with unique insights gained from lengthy personal experience of illness, as asserted by Kirsty; 'she was more than just a patient. Hannah was a girl on the cusp of becoming a woman and she knew what she wanted'.<sup>75</sup>

I argue that the common motif throughout the process of decision-making in Hannah's case was one of trust. As outlined in Chapter 1, according to Annette Baier trust relationships, rooted in the notions of vulnerability and interdependency, are the proper moral paradigm for good choices.<sup>76</sup> She contends that any capacity that a person may have for independent decision-making is primarily as a result of the caring relationships from which they emanate.<sup>77</sup> Some might say that Hannah was fortunate that time was on her side and afforded her the opportunity to change her mind. However, the building of trust enabled Hannah to take a measure of control over her own life,<sup>78</sup> and allowed her to have confidence in her own decisions, whether that was to refuse treatment or to later consent to it. Early and consistent participation in the decision-making process, beginning with her diagnosis with leukaemia at the age of 4, was key to building this trust. Hannah's mother was

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<sup>75</sup> Jones (n14) 218.

<sup>76</sup> Chapter 1, 72-74. Annette Baier, 'What do Women want in a Moral Theory?' in Roger Crisp and Michael Slote (eds) *Virtue Ethics* (OUP 1997) 245.

<sup>77</sup> See Chapter 1, 74.

<sup>78</sup> Wiener (n1) 715.

fully committed to becoming ‘engrossed’<sup>79</sup> in Hannah’s perspective, for example, when she supported Hannah’s objections to having blood taken from her thumb when it could have been removed from her central line.<sup>80</sup> This gradual and holistic view of competence would also accommodate concerns outside of the purely medical and acknowledge that sometimes relational needs might be more important to the child than their need for relief from physical distress.<sup>81</sup> Consider for example, the possibility that a dying child might be competent to refuse analgesia out of a desire to be conscious for family visits or to experience a special event,<sup>82</sup> even if they thereby suffered physical pain and distress.

The combination of lived experience of illness and creative latitude in decision-making shapes the character of the dying child. As Margaret Sommerville observes, the experience of living with illness can create maturity in the child that might not otherwise be present, although she is quick to note that such assessments of a child’s maturity are inevitably based upon the subjective values of those making the assessment.<sup>83</sup> In Hannah’s case, according to her mother, her mature characteristics manifest as determination, fearlessness in expression and the fact that she ‘could be equally as implacable in her actions when she’d made her mind up’.<sup>84</sup> Priscilla Alderson remarks that enduring treatment for long-term illness for 9 years had created a girl who was ‘remarkably wise’ and probably produced in her a form of expertise -

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<sup>79</sup> Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education* (University of California Press 1984).

<sup>80</sup> Jones (n14) 56.

<sup>81</sup> GMC (n20) para 3, notes that an aspect of safeguarding the ‘well-being’ of children includes treating them as individuals and respecting their views as well as considering their physical and emotional welfare.

<sup>82</sup> Kelly (n3) 318.

<sup>83</sup> Margaret Sommerville, *Ethical Canary: Science, Society and the Human Spirit* (McGill-Queens University Press 2004) 193.

<sup>84</sup> Jones (n14) 172.

knowledge of ‘what it is like to face death’.<sup>85</sup> As Anne Harris, Director of Care Services for the charity Rainbow Trust, notes, ‘in our rush to protect children from risk, adults don’t realize how profoundly children such as Hannah (...) understand their illness and the implications of further medical care’.<sup>86</sup> Indeed Hannah herself acknowledged that ‘I’m not a normal child 13 year-old (...) I’m a deep thinker. I’ve had to be, with my illness. It’s hard at 13, to know I’m going to die, but I also know what’s best for me’.<sup>87</sup>

Recognizing this expertise, I contend, produces a moral imperative on adult decision-makers to give great weight to the child’s choices. As Kirsty explains, ‘I could not force her to make a quick decision or deny her this final say in her destiny (...) this was Hannah’s choice’.<sup>88</sup> Whilst in daily healthcare practice this approach largely is, and should be welcome, at an institutional level it appears that it is much more difficult to adopt this kind of care thinking.<sup>89</sup> Health Officials lacked the crucial relational connection with Hannah as evidenced by Kirsty’s fears; ‘I thought of the hospital managers and lawyers (...) locked in rooms discussing the case of a *girl they didn’t know*’.<sup>90</sup> This absence of relationship meant that they were either unable to judge her competence in light of her capacities and experience, or the “relational distance” made it easier for them to discount her competence in order to save her life. Had the professionals become engrossed in and motivated to act on Hannah’s viewpoint, they might have concluded ‘how considered and certain a twelve year old

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<sup>85</sup> Priscilla Alderson as quoted in Barkham (n55).

<sup>86</sup> Barkham (n55)

<sup>87</sup> *ibid.*

<sup>88</sup> Jones (n14) 288.

<sup>89</sup> This can also be seen in institutional difficulties in applying care thinking to *parental* decision-making, as seen in the case of *R v Portsmouth Hospitals NHS Trust ex parte Glass* [1999] 2 FLR 905. See Jo Bridgeman, ‘Critically Ill Children and Best Interests’ (2010) 5(4) Clinical Ethics 184.

<sup>90</sup> Jones (n14) 258. Emphasis added.



could be'.<sup>91</sup> Nevertheless, it is doubtful that the courts would take a permissive approach. Despite the broad interpretations of best interests presented in the CA 1989<sup>92</sup> and the UNCRC,<sup>93</sup> it is more likely that the court would accede to the paternalistic desire to protect children, whether from pain and suffering or from making an 'unwise' decision.<sup>94</sup>

#### 4.2 - Hannah's Vulnerability and the Provision of Information.

Recognizing Hannah's vulnerability is a crucial aspect of viewing her situation under Guideline One. As discussed in Chapter 1, if we begin by adopting Fineman's construction of vulnerability as a 'universal, inevitable and enduring aspect of the human condition',<sup>95</sup> then it follows that at the most basic level for any person, adult or child, being a patient renders them vulnerable. By virtue of Hannah being a 12 year-old child, she clearly had certain additional situational vulnerabilities, such as emotional and financial dependence upon her parents.<sup>96</sup> This dependence may also render those who care for her vulnerable by their inability to help. Such parental vulnerability is apparent in Kirsty's statement as she reflected on 4 year-old Hannah's treatment for leukaemia; 'I wondered how high a price anyone could pay for being cured, let alone a child. Hannah was wracked with pain, and although I wished I could feel it for her, I couldn't'.<sup>97</sup>

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<sup>91</sup> *ibid* 264.

<sup>92</sup> See Children Act 1989 s1 (3).

<sup>93</sup> See UNCRC 1990, Articles 3 & 12.

<sup>94</sup> RCPCH (n20) .

<sup>95</sup> Chapter 1, 76-77. Martha Albertson Fineman, 'The Vulnerable Subject: Anchoring Equality in Human Condition' [2008] 20 Yale Journal of Law and Feminism 1,8.

<sup>96</sup> See Chapter 1, 76.

<sup>97</sup> Jones (n14) 45.

For the child, being a patient may compound such situational dependence or produce novel areas of vulnerability. With regard to the impact of ill-health on a child's competence, Watson et al assert that the relationship between illness and development is 'bidirectional' in that illness can delay development, yet as noted above, the experience that it brings may make the child seem 'old beyond their years'.<sup>98</sup> It is clear that children who live with chronic progressive conditions are necessarily forced into dependence and tend to be more socially isolated, as Hannah explains, '[n]ow I know I'm not exactly average: I'm thirteen and I've been in and out of hospital all my life'.<sup>99</sup> Yet, as noted in Chapter 2, vulnerability should not be viewed, in and of itself, as circumstance to be ameliorated or as a ground for denying competence and adopting a protectionist stance, but merely as another factor that makes up the particular circumstances of this particular child.<sup>100</sup> An analogy can be drawn between the position of dying children and that used by the courts for children who have had a strict religious upbringing, in order to argue that the child lacks sufficient life experience to attain competence. As discussed in Chapter 3, this was the approach taken in the early case law on *Gillick* competence, where the courts drew upon the child's religious environment to conclude that their ensuing 'sheltered upbringing',<sup>101</sup> or 'embarrassing convictions of callow youth',<sup>102</sup> meant that they were unable to reach the *Gillick* threshold.

However, as I also noted in Chapter 3, I am not persuaded by the courts' views on the impact of religious upbringing,<sup>103</sup> and I am less so in the case of children such as

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<sup>98</sup> Watson (n27) 532.

<sup>99</sup> Jones (n14) 39.

<sup>100</sup> Chapter 2, 117-120.

<sup>101</sup> *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810, [1999] 2 FCR 524.

<sup>102</sup> *Re E (A Minor) (Wardship: Medical Treatment)* [1992] 2 FCR 219.

<sup>103</sup> Chapter 3, 169.

Hannah, who have lived for many years with chronic conditions. I concur with the assertion made by the Joint Working Party report that these children ‘are emerging as individuals despite the difficulties arising from their illness’.<sup>104</sup> The evidence produced from the empirical work of Alderson and Montgomery that such children are in a position of *greater* insight and maturity, therefore justifying a greater degree of participation or a finding of competence at a lower age than is typical,<sup>105</sup> is the more compelling one. Indeed, research by Hinds et al demonstrates that children as young as 10 are able to make end of life decisions on serious issues such as Do-Not-Resuscitate (DNR) orders or the transition to palliative care.<sup>106</sup> Further, it may be questionable whether lack of ‘life experience’ is a meaningful measure in the context of end of life decision-making as the child will not have future opportunities to acquire additional experience in any event.

An important element of care that may increase or decrease a child’s vulnerability is the provision of information and the importance of “truth-telling”.<sup>107</sup> Here I am sympathetic to Kirsty’s view that from the beginning, open and honest communication was imperative to building a relationship of trust with her daughter,<sup>108</sup> as illustrated in this conversation between Kirsty and 4 year-old Hannah:

Hannah - ‘Will they make me better?’ Kirsty – ‘I paused for a moment. I had a choice now: lace the truth with uncertain hopes or speak it gently but honestly

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<sup>104</sup> Joint Working Party (n8) 15.

<sup>105</sup> Pricilla Alderson and Jonathan Montgomery, *Healthcare Choices: Making Decisions with Children* (Institute for Public Policy Research 1996).

<sup>106</sup> Hinds (n9) 9146.

<sup>107</sup> Anne Cote, ‘Telling the truth? Disclosure, Therapeutic Privilege and Intersexuality in Children’ (2000) 8 Health L J 199, 201.

<sup>108</sup> Cristie Cole and Eric Kodish, ‘Minors’ Right to Know and Therapeutic Privilege’ (August 2013) 15(8) Virtual Mentor 638, 640.

on this, my first step into the unknown with my daughter. Hannah had to trust me completely. I couldn't start lying to her now'.<sup>109</sup>

This began a consistent pattern of information-giving at a level appropriate to Hannah's understanding in order to alleviate some of her vulnerability and offer her 'a sense of control'.<sup>110</sup> By the age of 12, Kirsty was clear that Hannah had a *right* to information, noting that, 'Hannah simply wanted to know about who was doing what to her, how and when and her views deserved respect. She was the one who had to live all this'.<sup>111</sup> Such an approach is reflective of the Ethics of Care goal of attentiveness to the child as an individual and recognized the value of Hannah's embodied experience, as discussed in the next section below, and her desire and capability to receive and utilize information about her condition.

Of course, it is not inconceivable that the withholding of information may also be compatible with a 'caring' approach. It *is* true that some children may wish for decision-making to remain with their parents, who as experts in their own needs/the needs of their child can share their 'unique knowledge' with the professionals caring for that child.<sup>112</sup> In these cases the Ethics of Care could be used to scrutinise the relationship and to seek to discover whether there is genuine parental understanding of the child's anxiety or inability to understand the information or its implications,<sup>113</sup> or whether their veto was rooted in more self-serving motives. Healthcare law *does*

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<sup>109</sup> Jones (n14) 17.

<sup>110</sup> Hinds (n9) 9147.

<sup>111</sup> Jones (n14) 57.

<sup>112</sup> Jayne Price and Marisa McFarlane, 'Palliative care for children – a unique way of caring' in Jayne Price and Patricia McNeilly (eds) *Palliative Care for Children and Families: An Interdisciplinary Approach* (Palgrave Macmillan 2009) 9, 12.

<sup>113</sup> Joint Working Party (n8) 24.

allow for information to be withheld under the principle of therapeutic privilege,<sup>114</sup> which for adults is only on the grounds that to disclose would run a significant risk of substantial and immediate physical harm to the patient.<sup>115</sup> For children, a similar stance is affirmed in professional guidance, which also precludes non-disclosure merely to avoid upset or prevent a refusal of treatment.<sup>116</sup> This stands in contrast to a welfarist approach to the provision of information, which takes as its justification a paternalistic stance from the viewpoint of the *adults* involved in the decision-making. This accords with the view taken by those such as Ross who argue that even if a child is competent, there is a ‘morally significant difference’ between competent children and adults, and that in intimate families parental autonomy serves the needs and interests of the child and the family as a whole.<sup>117</sup> Such adult focused protectionism can be seen particularly in the early case law on *Gillick* competence,<sup>118</sup> which concluded that it was not necessary to ‘spell it out’ in relation to the nature of a 16-year old’s death from leukaemia,<sup>119</sup> nor was it ‘appropriate’ to reveal the grave manner of death awaiting a 14-year old burns victim.<sup>120</sup> In sum, the courts’ view was that to provide information that was deemed too distressing or complex could *exacerbate* the child’s vulnerability. Particularly in the context of dying, the case law seems to set a precedent of withholding information.

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<sup>114</sup> Kate Hodgkinson, ‘The Need to know- Therapeutic Privilege: A Way Forward’ (2013) 21 Health Care Anal 105, 112.

<sup>115</sup> See *Chester v Ashfar* [2005] 1 AC 134, per Lord Steyn para 16 and Department of Health, *Reference Guide to Consent for Examination of Treatment* (2<sup>nd</sup> edn, Department of Health 2009) 13.

<sup>116</sup> GMC, *Treatment and Care towards the End-of-life: Good Practice in Decision-Making* (2010) para 102.

<sup>117</sup> Lainie Friedman-Ross, ‘Arguments against Healthcare Autonomy for Minors’ (1995) Bioethics Forum 22, 23.

<sup>118</sup> *Re E* (n102); *Re L* (n101).

<sup>119</sup> *Re E* (n102) 224.

<sup>120</sup> *Re L* (n101) 526.

This in turn has a direct impact on the assessment of competence. The argument is circular in nature, in that assertions of incompetence become self-fulfilling as a result of the withholding information. As Elliston posits, failing to disclose was a deliberate strategy on the part of the doctors and the courts, which ‘provided a novel way of denying competence, by endorsing the withholding of information thought necessary to the decision-making process’.<sup>121</sup> It may be that past assumptions about child (in)competence mean that disclosure of information to children was seen as unimportant or that unacknowledged taboos around speaking about death,<sup>122</sup> even amongst healthcare professionals and the judiciary, act as a barrier to disclosure and give rise to the temptation to hide behind a more liberal interpretation of therapeutic privilege. Sometimes, it is the parents who request that the ‘truth’ not be disclosed to their child, potentially motivated by the same protectionist views as doctors and the courts;<sup>123</sup> the inability or lack of courage on their part to have the conversation; a cultural perception that bad news must not be shared and that ‘ignorance sustains hope’;<sup>124</sup> or even as a way of retaining an element of control themselves. But therapeutic privilege creates significant tensions between the patient’s right to autonomy, their position within family relationships, and the doctor’s duty to “do no harm”.<sup>125</sup> Even if these could be justified, the basis for non-disclosure is suspect, as informing any patient that they are dying is bound to cause upset, and I agree with Cote that this is not sufficient, as ‘upset does not necessarily translate into *harm*’.<sup>126</sup> In

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<sup>121</sup> Sarah Elliston, *The Best Interests of the Child in Healthcare* (Routledge-Cavendish 2007 ) 117.

<sup>122</sup> NHS England, Leadership Alliance for the Care of Dying People, *Engagement with Patients, Families, Carers and Professionals* (October 2013) 6.

<sup>123</sup> J Goldie et al, ‘Whose Information is it Anyway? Informing a 12-year-old Patient of Her Terminal Prognosis (2005) 31 *J Med Ethics* 427, 432 .

<sup>124</sup> Roy Gilbar and Jose Miola, ‘One Size Fits All? On Patient Autonomy, Medical Decision-Making and the Impact of Culture’ (2014) *Medical Law Review*, 3. Published Online First (16 December 2014) doi:10.1093/medlaw/fwu032, 5.

<sup>125</sup> Claude Richard et al, ‘Therapeutic Privilege: Between the Ethics of Lying and the Practice of Truth’ (2010) 36 *J Med Ethics* 353.

<sup>126</sup> Cote (n107) 209.

any event, in most cases the expected outcome of giving information about the dire consequences of refusing treatment would be to spur on the patient to consent to the treatment that the doctors and court wish them to receive.

Hannah's case is different in that the provision of information enabled her to *refuse* treatment with full knowledge of the consequences. Applying Guideline One allowed the doctors to be freed from paternalistic generalizations about what is 'appropriate' to disclose to a child of a certain age and adapt their approach to meet the needs and understanding of Hannah - the actual child in front of them.<sup>127</sup>

In light of the Ethics of Care's aims to respect a child's capabilities and foster participation, Hannah's parents and doctors recognized the value in disclosure, as Kirsty explained; 'Hannah must know the complete truth and I had to speak it. To make a choice, she had to know everything'.<sup>128</sup> This is especially important in the context of end-of-life care, where according to Hinds et al, the provision of information and answering of questions was the factor most frequently identified as a 'helpful staff behaviour' by children who were tasked with making end-of-life decisions.<sup>129</sup> Additionally research shows that for the healthcare team, clarity and honesty when information is being imparted is key to successful working relationships.<sup>130</sup>

Such candour is not without cost however, and Kirsty acknowledged her personal discomfort and fear that full truth-telling, as well as promoting trust, could act to undermine it when the news was bad. For example, this fear was realized when Kirsty

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<sup>127</sup> Hodkinson (n114) 122.

<sup>128</sup> Jones (n14) 291.

<sup>129</sup> Hinds (n9) 9149.

<sup>130</sup> P Hinds et al, 'A Comparison of Stress Response Sequence in New and Experienced Paediatric Oncology Nurses' (1994) 17 *Cancer Nurs* 61.

had to explain to Hannah that her pace-maker operation had not been a complete success. She recalls that ‘breaking another piece of bad news worried me. Hannah’s trust in me had always felt complete but I wondered if it was being tested to its limits now’.<sup>131</sup> The judgment required in such situations should be informed by the caring relationships in the child’s life, which can act as a support to those involved in the difficult process of disclosure. As Baier notes, the benefit of viewing relational trust as the core of moral decision-making is that any autonomy which the child possesses as a ‘second person’ out in the wider world, is a product of the ‘first person’ they are, nurtured from early and consistent experience of trusting relationships.<sup>132</sup> Indeed, the benefits of open and honest communication most often outweigh the disadvantages, as noted by Sibson et al, who assert that whilst ‘professionals can sometimes be reluctant to undertake such frank discussion’, that ‘knowing what to expect and having a clear plan of what to do as the situation changes can enable families to cope better’.<sup>133</sup>

#### 4.3 - Hannah’s Embodied Experience.

As discussed in Chapter 2, a focus on the child’s embodied experience of treatment and care is another crucial aspect of attentiveness to her as an individual, as it brings the child’s bodily experience to the forefront of decision-making, reflects the importance of body image as a means of identity and may acknowledge a means of communication as the child moves through the physical world.<sup>134</sup> In Hannah’s case, the administration of medicines, performance of surgery and the receipt of physical touch and emotional care as felt through her body, would have informed her particular

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<sup>131</sup> Jones (n14) 214.

<sup>132</sup> Chapter 1, 73-75 Baier (n76).

<sup>133</sup> Keith Sibson, Finella Craig and Ann Goldman, ‘Palliative Care for Children’ in C Faull et al (eds), *Handbook of Palliative Care* (2<sup>nd</sup> edn, Blackwell Publishing 2005) 301.

<sup>134</sup> Chapter 2, 117-120



expertise. In turn, the reality that the impact on her body of any choice she made was always at the forefront of her mind would go some way towards explaining why Hannah made the decision she did. She notes:

I've had to think about my body all my life and knew they meant that I wouldn't get better without a transplant. But I didn't want to see any more doctors or have anyone else looking in on my life. I'd had enough of that.<sup>135</sup>

Paradoxically, the very physical interventions that were necessary to save her life were at the same time, from Hannah's perspective, destroying it. Additionally those in close relationships of care with Hannah were subjected to the trauma of observing the physical effects of the treatment without fully comprehending its embodied effects. This is illustrated by Kirsty, as she remembers 4 year-old Hannah receiving chemotherapy for leukaemia:

Hannah's senses were so heightened that her skin was incredibly sensitive and I found it hard not to physically reassure her (...) But Hannah did not want to be hugged and she did not cry out for me either. She lay in a cocoon of silence, as if willing herself to live (...).<sup>136</sup>

Here the bodily experience of pain acted as a barrier to the physical expression of care through touch that was needed by both the 'cared-for' and the 'one-caring'. This barrier took the form of Hannah turning within herself, which she appears to have used as a coping mechanism. This was especially disturbing for her mother, as she

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<sup>135</sup> Jones (n14) 224.

<sup>136</sup> *ibid* 21.

recounts that Hannah's 'silence was almost worse than screams'.<sup>137</sup> Lack of communication presents a novel problem for the application of the Ethics of Care in terms of how to care without reciprocity, and Kirsty's experience reveals that care sometimes compels one to stand back and do nothing.

By the time Hannah was 12, Kirsty's experience gained from care had deepened, so that she was able to understand that Hannah's embodied experience consisted of more than her physical sensations. Upon seeing Hannah's pain as she went into heart failure, Kirsty questioned 'How long could her body cope with this? And, more importantly, how long could her spirit?'<sup>138</sup> A mother's concern was centred more upon the emotional and relational damage than the physical implications. Specifically she recognized the implications, should Hannah be deemed incompetent, of being compelled to receive and live with another's heart. John Harris observes the practical difficulties, such as forcibly removing Hannah from her parents, placing her in protective custody, submitting her to a major surgical procedure and requiring subsequent invasive treatments, all with no guarantee of success. His view that it was 'very unlikely that would be judged in her best interests by any sane person' is a persuasive one and I concur with him that in light of her embodied experience, it was 'perfectly rational and consistent with her best interests to want to die peacefully at home'.<sup>139</sup>

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<sup>137</sup> *ibid* 21.

<sup>138</sup> *ibid* 193.

<sup>139</sup> John Harris quoted in Barkham (n55).

#### 4.4 - Making Advance Decisions

A final question to consider is whether a child should be able to make advance decisions about their care. This could take the form of Advance Care Planning (ACP), which is the process of setting out requests or other ‘statements of values, wishes, priorities or preferences’ relating to future care or treatment.<sup>140</sup> Here, our focus is on ‘Advance Decisions’ (AD), which are distinguished as ‘a special type of advance statement that represents an actual decision to refuse treatment’ in the event that the patient lacks capacity.<sup>141</sup> In Hannah’s case, a legally binding DNR instruction *had* been entered into her medical notes, although this seems to have been a routine consequence of her refusal of the transplant rather than a direct request.<sup>142</sup> Whilst there is no evidence that Hannah or her family ever considered making an AD to the effect that she wished to refuse a heart transplant, it is instructive to consider the legal and ethical position had she wished to do so.

The regulation of AD’s is found within the Mental Capacity Act 2005, which contains specific protections for the refusal of life-saving treatment.<sup>143</sup> Whilst the BMA’s Consent Toolkit notes that ‘any person can make an Advance Decision including an individual under the age of 18’,<sup>144</sup> the MCA 2005 s24 declares that in order for the AD to be *legally binding* it must have been made by a person who has capacity and is aged over 18.<sup>145</sup> The basis and justification for a blanket ban on children’s AD’s can surely be questioned. UK case law is silent on the issue, however there is precedent in

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<sup>140</sup> National Council for Palliative Care and NHS End of Life Care Programme, *Advance Decisions to Refuse Treatment: A Guide for Health and Social Care Professionals* (Sept 2008) 2.

<sup>141</sup> Explanatory Notes to the Mental Capacity Act 2005 – s24.

<sup>142</sup> Jones (n14) 230

<sup>143</sup> See MCA 2005 S 25(5) which states that the AD must be verified by a statement that the patient recognizes that they are refusing life-saving treatment and S25(6) which states that the Act states that the AD must be in writing, signed and witnessed.

<sup>144</sup> BMA Consent Toolkit, Card 9 – Advance Decisions, Para 3. <bma.org.uk/practical-support-at-work/ethics/consent-tool-kit> < accessed 12 January 2015>.

<sup>145</sup> MCA 2005 s 24(1).

the USA, with two cases involving advance planning. However neither had formal AD's but rather turned on the children's orally expressed wishes.<sup>146</sup> Both involved older adolescents (aged 15 and 17) in a Persistent Vegetative State (PVS) after a car accident, and in both the parents wished for ANH to be removed. The parents drew upon prior conversations that they had had with their children, to the effect that if they were ever in an irreversible coma they would not wish to remain alive. This was sufficient for the courts to be able to rule that ANH should be removed as 'when a mature teenager expresses conscientious decisions regarding his medical treatment, the court is bound by those decisions'.<sup>147</sup>

Returning to this jurisdiction and in the context of mid-childhood, the first reason that children are not permitted to make legally binding AD's may be a pragmatic one.

Nikola Stepanov has noted that whilst ACP and AD's are useful tools for adults, they have been less well used for children, and raises the concern that a child's presumed lack of capacity may act as a barrier to raising the issue of advance planning with them at all.<sup>148</sup> Second, the stance taken in the MCA appears to build upon the case law discussed above, which holds that it is impermissible to allow children who are *Gillick* competent, even at the time of the proposed treatment, to refuse that treatment if it would endanger their life to do so. The legislative presence of a multitude of safeguards; from the requirement of very specific level of detail as to the nature of the refusal,<sup>149</sup> to the proviso that the AD will not be valid if the patient has done anything

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<sup>146</sup> *In re Chad Swan* (1990) 569 A 2d 1202; *In re Guardianship of Meyers* (1993) North East Rep Second Ser, Feb26; 610: 663-71.

<sup>147</sup> Lauren McAliley et al, 'The Use of Advance Directives with Adolescents' (2000) 26(5) Pediatric Nursing 471, 472.

<sup>148</sup> Nikola Stepanov, 'End-of-life care: How terminally ill kids and their parents can plan for a better death' (4 Nov 2014) *The Conversation* <[theconversation.com/end-of-life-care-how-terminally-ill-kids-and-their-parents-can-plan-for-a-better-death-32379](http://theconversation.com/end-of-life-care-how-terminally-ill-kids-and-their-parents-can-plan-for-a-better-death-32379)> < accessed 18 Nov 2014>

<sup>149</sup> MCA 2005 s 25(4), (5), (6).

else clearly inconsistent with it remaining his fixed decision,<sup>150</sup> are in place in order to protect the adult patient from the improper application of an AD. However, some have concerns that, even for adults where AD's *are* legally binding, in practice they are poorly implemented.<sup>151</sup> For children this argument would be stronger still as their positions are further complicated by the assertion that their views are more likely to be changeable, that these kinds of decisions should rest with their parents or they do not have enough life experience to be able to make legally binding decisions.<sup>152</sup> It would seem highly unlikely that a court would be prepared to uphold an AD when they are loathe to permit conscious, competent children to refuse life-saving treatment. Third, the blanket ban may be another reflection of the taboo surrounding talking to terminally ill children in advance about their deaths,<sup>153</sup> or that to do so may signal a removal of hope.<sup>154</sup> Although in Hannah's case her parents were very clear that a decision to refuse treatment should be Hannah's to make, the inner conflict they experienced is clear in Kirsty's statement that:

Even though I knew that was the ultimate consequence of Hannah's decision,  
a gulf can separate what we know to be true and what our hearts still resist.  
Even as the wheels had ground into motion for giving Hannah palliative care  
at home... I'd resist thinking about her possible death.<sup>155</sup>

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<sup>150</sup> MCA 2005 s 25(2)(c).

<sup>151</sup> Matthijs P S Van Wijmen, 'Continuing or Forgoing Treatment at End of Life? Preferences of the General Public and People with an Advance Directive' (2014) *J Med Ethics* 1. First Published Online 2 September 2014 doi: 10.1136/medethics-2013-101544.

<sup>152</sup> See Laine Friedman Ross, *Children, Families and Health Care Decision Making* (Clarendon Press 1998).

<sup>153</sup> McAleily (n147) 472.

<sup>154</sup> Karen Horridge, 'Advance Care Planning: Practicalities, Legalities, Complexities and Controversies' (2014) *Arch Dis Child* 1, 2. First Published Online 1 October 2014 doi:10.1136/archdischild-2014-305945.

<sup>155</sup> Jones (n14) 230.

If this was the case when Hannah refused a heart transplant after suffering acute heart failure, the question arises as to whether it would be more or less distressing to her parents for her to have made such a decision far in advance. Looking at the issue through the lens of the Ethics of Care, there may be some grounds to argue that children like Hannah should be able to make legally binding AD's as part of their end-of-life care. Whilst the rationale for the ban clearly does apply to some children, this fact alone should not be enough to justify a blanket ban on legally binding AD's for *all* children. Indeed, McAliley et al express skepticism that there is any developmental significance in turning 18 when it comes to making end-of-life decisions.<sup>156</sup> By applying Guideline One as was done in sections 4.1 and 4.2 in relation to competence and provision of information, it may be apparent that a particular child is *Gillick* competent and has sufficient life experience as a result of their illness to understand the nature and implications of an advance refusal. This could be clearly documented as part of the AD and the safeguards that are in place to protect adults from its improper application could equally be applied to children.<sup>157</sup>

## **Section 5 - Applying Guideline Two: *Consideration of the Child's Past and Future Caring Relationships* - What were Hannah's Best Interests?**

### **5.1 - Relational Best Interests and Collaborative Decision-Making**

If the Health Authority officials had been successful in compelling Hannah to return to hospital for treatment, then this would presumably have been on the basis that they

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<sup>156</sup> McAliley (n147) 472 & 480.

<sup>157</sup> See MCA 2005 s24-26.

were satisfied that the usual presumption of child incompetence to refuse consent to treatment should have stood in her case. Accordingly, any decision about her care would then have been taken in her best interests. This could be by applying the Welfare Checklist found section 1(3) of the Children Act 1989 if there was an application for a Specific Issue order, or more likely by an assessment of her interests, welfare, or well-being under the inherent jurisdiction of the courts.<sup>158</sup> Whilst the systematic review in Chapter 3 demonstrated that despite proposing a holistic interpretation of best interests the courts find it ‘incredibly difficult to distance themselves from medical opinion’,<sup>159</sup> it is less clear how best interests might be constructed at the end-of-life. For Baines, working within the context of a sophisticated western healthcare system, if a largely medical paradigm is adopted it would be almost impossible to say that it was in an incompetent child’s best interests to be allowed to die.<sup>160</sup> He concludes that best interests would point all one way – that treatment, however aggressive, should be continued.<sup>161</sup> However, our moral intuition, and relational and spiritual inclinations, may suggest otherwise. The Health Authority officials in Hannah’s case appeared to have adopted Baines’ thinking, yet her mother’s exasperated questioning - ‘Why was the hospital doing this? How could they think this was in Hannah’s best interests? Everyone knew what she wanted’,<sup>162</sup> reveals the presence of “care” thinking within the family. Indeed, I suggest that in situations where there is little ‘medically’ that can, or perhaps more importantly *should* be done for the patient, relational concerns should come to the fore. This concurs with empirical evidence from a study conducted by Talati et al, on paediatricians reactions

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<sup>158</sup> See *Re JM* [2015] EWHC 2832 Mostyn J, for a discussion of when the court will use a Specific Issue Order versus exercising its inherent jurisdiction.

<sup>159</sup> Rob Heywood, ‘Parents and Medical Professionals: Conflict, Cooperation and Best Interests’ (2012) 20 Medical Law Review 29, 38.

<sup>160</sup> Paul Baines, ‘Death and *Best Interests*’ (2008) 3 Clinical Ethics 171,173.

<sup>161</sup> *ibid* 174.

<sup>162</sup> Jones (n14) 257.

to refusals of treatment by children, which confirms that when the prognosis is poor and child and parental refusal concur, doctors are more likely to deem such a refusal in the child's overall best interests, even if not in the child's best medical interest.<sup>163</sup>

One key factor in fostering a relational approach to best interests is understanding the interconnectedness of the child with those who care for her and recognizing the reality that within end-of-life decision-making family involvement has a much higher profile in the case of dying children than for adults.<sup>164</sup> A 'partnership of care'<sup>165</sup> between doctors and family would acknowledge that collaborative communication is essential, as it helps to support the child in developing relationships and understanding their core personal values.<sup>166</sup> By ascertaining the child's and families 'tolerance for assuming responsibility' for decision-making,<sup>167</sup> participation can have the benefit of acknowledging the child's particular needs in her relational context and affording the child and family a sense of control over what remains of the child's life.<sup>168</sup>

Rather than positioning the patient and their family as separate entities, as Price and McFarlene note, a collaborative approach considers how the needs and values of the family may impact on the child 'influencing his or her life, development and belief system' and 'forms the child's meaning of life, illness and death'.<sup>169</sup> For example, the psychosocial wellbeing of the patient may improve or deteriorate depending upon

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<sup>163</sup> Erin D Talati, Colleen Walsh Lang & Lainie Friedman Ross, 'Reactions of Pediatricians to Refusals of Medical treatment for Minors' (2010) 47(2) J Adolesc Health 126.

<sup>164</sup> Jayne Price et al, 'Paediatric Palliative Care in the UK: Past, Present and Future' (2005) 11(3) International Journal of Palliative Nursing 124.

<sup>165</sup> RCPCH (n20) 15.

<sup>166</sup> Helen Bennett, 'Ethical Issues' in J Price and P McNeilly (eds) *Palliative Care for Children and Families: An Interdisciplinary Approach* (Palgrave Macmillan 2009) 68.

<sup>167</sup> RCPCH (n20) 27.

<sup>168</sup> Ruth Davies, 'Caring for the child at the end of life' in Price J and McNeilly P (eds) *Palliative Care for Children and Families: An Interdisciplinary Approach* (Palgrave Macmillan 2009) 179.

<sup>169</sup> Price (n112) 9.



their perception of how well the worries and fears of their family members are being addressed. Likewise an individual patient's spiritual needs may be intimately interconnected with the spiritual standing and beliefs of their family members.<sup>170</sup> These family values may play into the weight certain considerations might be given in the balancing exercise that often forms the best interests assessment. Empirical research by Hinds et al reveals that for 19 terminal cancer patients aged between 10-20, the first and 'nearly universal'<sup>171</sup> factor that influenced their end-of-life decision-making was 'thinking about my relationships with others', whether that was with family, staff or future patients.<sup>172</sup> For example the child may have an interest in how her family remembers her after she has died<sup>173</sup> and this concern may be an expression of the child as 'one-caring'.<sup>174</sup> Likewise for their parents the primary factor was 'deciding as my child prefers'.<sup>175</sup> Thus the study was able to reach a clear conclusion that 'human relationships strongly influence end-of-life decisions [in pediatric oncology]'.<sup>176</sup> This attitude was revealed by Kirsty in Hannah's case, as she recounted that:

When Hannah was young and unable to tell me clearly what she wanted, I'd done what I thought was best for her. But now she knew for herself, and however closely I had walked by Hannah's side I had not walked in her shoes: she was the person who had lived with this for so long – and now could die

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<sup>170</sup> For example, members of The Church of Jesus Christ of Latter-Day Saints believe in the salvation of family units, where spouses and children are 'sealed' together for the eternities. The validity of this 'sealing' is dependent upon the 'worthiness' in the form of adherence to the Church's doctrine and practices of each of the family members.

<sup>171</sup> Hinds (n9) 9153.

<sup>172</sup> *ibid* 9150.

<sup>173</sup> Baines (n160) 174.

<sup>174</sup> Noddings (n79).

<sup>175</sup> Hinds (n9) 9151.

<sup>176</sup> *ibid* 9153.

with it too. If a transplant was too high a price for her to pay then I would accept that, however hard it was for me.<sup>177</sup>

Again, the value of trust plays an important role, as the child understands that those in caring relationships with her will seek to fight for what they, and the child, thinks is ‘best’. This was important to Hannah as she claimed that ‘my mum and dad trusted me as well, and I sometimes think adults should do it more (...) good children should be listened to and believed. It’s about respecting them.’<sup>178</sup> It was this value that Kirsty feared would be undermined when the Health Authority officials sought to take decision-making out of their hands, as she notes, ‘the idea that her trust in Andrew and me might be shattered was horrifying: we were the people who protected her, home was the place where she felt safe, and now it was under threat’.<sup>179</sup> Kirsty’s response to Hannah’s fear at having her parents make the decision for her, that they ‘couldn’t feel guilty if we tried our best because that’s all anyone can ever do’<sup>180</sup> demonstrates that the simple competence or incompetence binary is not sufficiently subtle to deal with cases such as Hannah’s. Instead, the provision of this “safe space” based on trust and interdependence is better able to accommodate the complexity of mid-childhood decision-making, with its interplay between the quest for independence, the need for familial support and the desire on the part of the child to protect loved ones from guilt, by refraining from asking them to make the decision.

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<sup>177</sup> Jones (n14) 221.

<sup>178</sup> *ibid* 226.

<sup>179</sup> *ibid* 264.

<sup>180</sup> *ibid* 292.

## 5.2 - The Position of Parents, Siblings and the Future Impact of the Decision

The relationship of the child with their siblings and the future impact of the decision upon the family is a vital, but often overlooked consideration in end-of-life decision-making. The reality is that many parents confronted with tragic circumstances such as Hannah's, will also be juggling the needs of any other children; in her case her three younger siblings, as well as trying to meet their own individual needs. As it was her parents and siblings who had to live with the future implications of Hannah's choice to refuse the transplant, I concur with Isaacs that the effect on their lives is 'surely morally relevant' in the decision-making process.<sup>181</sup> Indeed, I contend that best interests in this context can be stretched even further to find that an altruistic motivation on the part of the child to put their families needs first could form part of the construction of 'best'.

Siblings, in particular, can be a 'crucial axis in the family'.<sup>182</sup> Kirsty recalls how it was Hannah's younger sister Lucy who 'pushed Hannah and bolstered her determination to do as much as possible' and that all three siblings had become remarkably resilient as they 'had known nothing other than her sister's illness'.<sup>183</sup> Whilst, the needs of a sibling to a dying child are understandably viewed as less important, this is 'often at an emotional and psychological cost to them'.<sup>184</sup> Kirsty would counter this, by referring to the positive qualities that Hannah's siblings had developed by living with an ill sister, for instance 'how considerate and patient they

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<sup>181</sup> David Isaacs, 'Ethics of paediatric end-of-life decision making and consent for publication' 2014 J Med Ethics doi 10.1136/medethics-2014-102235, 1

<sup>182</sup> B Sourkes et al, 'Food, Toys and Love: Paediatric Palliative Care' (2005) 35 *Current Problems in Pediatric Adolescent Health Care* 350.

<sup>183</sup> Jones (n14) 272.

<sup>184</sup> Fiona Collinson and Karen Bleakley, 'Supporting Children and Families' in J Price and P McNeilly (eds) *Palliative Care for Children and Families: An Interdisciplinary Approach* (Palgrave Macmillan 2009) 119.

were with less able children', and learning 'how to stick up for someone who stood out'.<sup>185</sup> Yet, siblings of a dying child inevitably receive less attention from their parents than they would otherwise have done, which Edwards and Davis call a form of 'benign neglect'.<sup>186</sup> The picture can be complicated further by resentment of siblings by the sick child and a desire to have their parents "all to themselves", as was the case for Hannah when she confessed that 'I wish they weren't there because then Mum could spend the whole day with me (...) I know a lot of her attention goes on me, I still sometimes wish I didn't have to share her or dad with my brothers or sisters'.<sup>187</sup> Additionally, there is the reality that some siblings feel different from their peers; guilty, anxious or unsure of what is expected of them.<sup>188</sup> This is particularly so where sibling relationships are often strong and a sibling becomes the main confidante of the sick child. Underlying complexities are present in siblings' worries about their parent's coping abilities and the need to pursue their own lives whilst remaining anxious about their sibling.<sup>189</sup> I contend that all of these considerations are persuasive grounds for bringing their needs into the best interests assessment.

## **Section 6 - Applying Guideline Three – Evaluation of the Social**

### **Context of Care**

Finally, Guideline Three - Evaluation of the Social Context of Care, makes space for us to consider wider questions relating to the role of medical professionals in society, the meaning of parental responsibility in the context of "care", how far society is prepared to go in permitting children to have control over their own health and what

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<sup>185</sup> Jones (n14) 174.

<sup>186</sup> M Edwards and H Davis, *Counselling Children with Chronic Medical Conditions* (British Psychological Society 1997).

<sup>187</sup> Jones (n14) 161.

<sup>188</sup> Collinson (n184) 120.

<sup>189</sup> Joint Working Report (n8).

impact religion or culture should play in decision-making. It is notable that those that are deemed to bear responsibility for these judgments as they operate at an institutional, societal and media level, might be said to be those who are without “care”. The absence of a close relational connection upon which to base judgments which might ultimately override those which *were* made within the nexus of relationship, reveals the difficulty of applying care thinking at this level. Yet this third guideline is crucial in order to place the other two guidelines into context, and it provides scope to consider the place of ‘justice’, discussed in Chapter 1, that is needed to temper some of the overreaches of care.

First, it involves a scrutiny of the quality of care and the motivations of those caring and addresses wider social and policy questions of what we *should* do. Kirsty found such scrutiny particularly difficult, as she confides that ‘maybe I should have been afraid all along that something like this would happen, prepared myself for it because I had always known that there were those who couldn’t understand Hannah’s choice – and my support of it perhaps even more so.’<sup>190</sup> At the same time, she could appreciate that scrutiny could bring positive benefits in the form of the wider social value of Hannah’s stand, in that ‘[i]f Hannah’s decision inspired another parent to have the courage to make the right one for their child, even if it meant going against the collective wisdom, then she would make a mark on the world few children had the opportunity to create’.<sup>191</sup>

The social context of care may also prompt us to consider the other important caring relationships in Hannah’s life – those with the healthcare team. Although, close

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<sup>190</sup> Jones (n14) 258.

<sup>191</sup> *ibid* 277.

relationships of care with healthcare professionals would fall to be considered under Guideline Two, there are wider social questions about the role of doctors in decision-making. For example, Hannah's refusal raises clear tensions for doctors with their obligations under the Hippocratic Oath to keep patients from harm.<sup>192</sup> Whilst this may be seen as a justification for the health officials' choice to go to law, I agree with Barkham's observation that the case raises doubts as to 'how well-equipped are our medical and legal systems to tackle private tragedies, where living with invasive treatment is felt to be worse than dying?'<sup>193</sup> This then feeds into questions about how far society is prepared to allow a child to participate in decision-making. Under Guideline Three, wider religious, social or cultural networks of care may be utilised here to help facilitate, for example, the provision of information, either by potentially uncovering cultural or social practices that underlie the reluctance to disclose,<sup>194</sup> or offering alternative sources of support to help facilitate disclosure. Additionally, greater attention could be paid to the detriment or benefit caused by illness to the "spiritual" aspects of the child's life, as I contend that religious belief and spiritual identity form part of a view of social "good". Ill-health might impact upon the way that the child operates in the social world or the value that she places upon her own life. For Hannah, it was the desire to have joy in her life and connection to others. She noted that 'I'd like to live just one day without having to rest when my heart gets tired: I'd just waste my energy, doing stuff with friends'.<sup>195</sup> Her refusal could be viewed as way of controlling how she wished to be remembered, summed up in her declaration 'my decision wasn't about dying. It's about living.'<sup>196</sup>

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<sup>192</sup> Comments by Fiona Stewart, Paediatrician at Belfast City Hospital in Barkham (n56).

<sup>193</sup> Barkham (n56)

<sup>194</sup> Richard (n125) 356.

<sup>195</sup> Jones (n14) Back cover.

<sup>196</sup> *ibid*

Likewise, in terms of advance decision-making, a wider conception of ACP could shift the focus away from the filling of forms towards the ‘social process’<sup>197</sup> of preparation for death by including wider networks of connection and influence on the child’s life. Open, honest and complete communication as a priority of care,<sup>198</sup> may enable the family to consider the options, obtain relevant information,<sup>199</sup> and prepare to make decisions about other aspects of the process, such as post mortem, which can be helpful to the family and guard against any misunderstandings later on.<sup>200</sup> This social process could also be beneficial to the caring dynamic by helping healthcare professionals to understand the child better and provide a structure within which to have difficult conversations. I concur with Stepanov here, that a key benefit of the child’s involvement in ACP would be the opportunity to identify any differences between the types of treatments that parents might want and what the child is prepared to endure, so they can be negotiated and resolved earlier,<sup>201</sup> thus often avoiding recourse to law.

### **Concluding Thoughts**

This case study has demonstrated that end-of-life decision-making has special relevance in mid-childhood. In Hannah’s case, although the close relationships that she had both with her parents and the treatment team, and a particularist interpretation of professional guidelines, enabled an effective handling of these issues, once intervention at the institutional and societal level occurred, the nuances of the care approach were lost. The analysis of Hannah’s narrative has revealed that the

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<sup>197</sup> Arianne Brinkman-Stoppeleburg et al, ‘The Effects of Advance Care Planning on End-of-Life Care: A Systematic Review (2014) 28(8) *Palliative Medicine* 1000, 1001.

<sup>198</sup> E C Meyer et al, ‘Improving the Quality of End-of-Life Care in the Pediatric Intensive Care Unit: Parents’ Priorities and Recommendations’ (2006) 117(3) *Pediatrics* 649.

<sup>199</sup> Stepanov (n148),

<sup>200</sup> Davies (n168) 181.

<sup>201</sup> Stepanov (n148).

difficulties evident in ascertaining child competence and determining best interests that were discussed in Chapter 3 are in fact both amplified and diminished in the context of end-of-life decision-making. Amplification of the difficulties comes from a realization of the finality of the consequences of the decision; the preparing for death whilst hoping for a miracle; the ‘feelings of acceptance and denial’ that become part of the paradox of daily life.<sup>202</sup> Conversely some of the ethical wrangling appears to be diminished when it is clear that preserving life is no longer possible, especially when concerned with a child like Hannah who Kirsty testifies ‘knew her own mind in a way that astounded me and had an utter self-belief in what she thought she was right’.<sup>203</sup> By applying the three guidelines of the Ethics of Care room is freed up for more creative decision-making and appreciation for relational concerns, which in other cases are obscured by the quest to preserve both life and the child’s right to an ‘open future’.

Above all else, this study of end-of-life decision-making by and for children such as Hannah, has revealed that viewing each child as an interconnected individual in her particular relational circumstances, as advocated by Guideline One, is imperative to good decision-making by both healthcare professionals and the courts. It is perhaps by starting with an orientation of care and citing moral value in relational connection, that as Brierley and Larcher reflect, we have the ‘means to recognize the interdependence of the individual in a family, social and cultural group’ and a mechanism ‘better suited to the poignant dilemmas that may arise in critical care settings’.<sup>204</sup>

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<sup>202</sup> Jones (n14) 231.

<sup>203</sup> *ibid* 174.

<sup>204</sup> Joe Brierley and Vic Larcher, ‘Cui bono? Can Feminist Ethics show a Path in Complex Decision-Making where ‘Classical’ Theories Cannot?’ (2011) 6 (2) *Clinical Ethics* 86. 90.



**CHAPTER 5**

**LIVING ORGAN DONATION BY CHILDREN**

**IN MID-CHILDHOOD**

**CASE STUDY TWO**

*‘How likely psychological benefits are to occur depends on individual values (...) consent that emanates from deep affection and concern may reflect autonomy just as surely’<sup>1</sup>*

**Introduction**

The issue of whether one living individual should donate an organ in order to save the life or health of another is infused with narratives of altruistic heroism. Combine this with deep-seated questions surrounding the nature and extent of the notion of sacrifice, and the purpose and value of bodily integrity and we are confronted with a problem of profound legal and ethical complexity. Never is this more apparent than when the donor in question is a child.

The literal and symbolic importance of the bodies of those closest to us was bought forcefully into the public consciousness by the Bristol Royal Infirmary and Alder Hay scandals.<sup>2</sup> Organs and tissues from children who died at the hospitals between 1988

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<sup>1</sup> Aaron Spital and James Stacey Taylor: Living Organ Donation: Always Ethically Complex’ (2007) 2(2) CJASN 203.

<sup>2</sup> The Kennedy Report, *The Report of the Public Inquiry into Children’s Heart Surgery at the Bristol Royal Infirmary 1984- 1995: Learning from Bristol* (Cm 5207 July 2001); The Redfern Report, *The Royal Liverpool Children’s Inquiry Report – Summary and Recommendations* (2001).

and 1996 were removed and retained without parental knowledge or consent.<sup>3</sup> As Jo Bridgeman has described, parents felt ‘abject horror’ and ‘raw distress’,<sup>4</sup> at what they viewed to be a violation,<sup>5</sup> and she is right to claim that its significance lay in ‘the particular value attributed to the child and the intimate relationship between children and those caring for them in our society’.<sup>6</sup> As Floris Tomasini observes, it was so psychologically damaging for the parents because the body parts of their children held symbolic significance as a memorial to the ongoing personal relationship they had shared.<sup>7</sup>

Whilst the Alder Hay scandal involved the bodies of deceased children, these themes of the relational importance of the body are evident to an even greater extent within the focal topic of this chapter – *living* child organ donation. Whilst in theory legally permissible,<sup>8</sup> living organ donation by children is almost unheard of in practice in the UK.<sup>9</sup> This may be attributed, at least in part, to the view held by many clinicians that living organ donation is ethically contentious as it impinges on their duty of non-maleficence by subjecting their patient to a procedure which is in itself ‘designed to make the well sick.’<sup>10</sup> This is compounded by concerns as to whether children could ever be competent to make a decision as serious as organ donation, with its potential life-long impact on health, when they lack life-experience or the ability to fully

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<sup>3</sup> Jane Fortin, *Children’s Rights and the Developing Law* (3<sup>rd</sup> edn, CUP 2009) 386.

<sup>4</sup> Jo Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (CUP 2007) 2-3.

<sup>5</sup> Jo Bridgeman, ‘“Learning from Bristol”: Healthcare in the 21<sup>st</sup> Century’ (2002) 65(2) *Modern Law Review* 241.

<sup>6</sup> Bridgeman (n4) 3.

<sup>7</sup> Floris Tomasini, ‘A Historical Long View of Posthumous Harm: Comparing Organ Snatching to Body-Snatching’ *The Power of the Criminal Corpse*, University of Leicester (16 May 2016) <staffblogs.le.ac.uk/crimcorpse/2016/05/16/organ-and-body-snatching>

<sup>8</sup> See Human Tissue Act 2004, s2.

<sup>9</sup> Stephen D Marks, ‘Should Children ever be living Kidney Donors - Editorial?’ (2006) 10 *Pediatric Transplantation* 757.

<sup>10</sup> David Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (CUP 2009) 205.

envision their future life. Additionally, there may be a general squeamishness surrounding the proposition of children acting as donors, arising from the adoption of ‘romantic developmentalism’ as the prevailing paradigm of childhood, as discussed in Chapter 2.<sup>11</sup> Stemming from ‘deeply distressing concerns related to the “cutting up” of the body’<sup>12</sup> held by parents, and perhaps to a lesser extent healthcare professionals themselves, adopting this paradigm fosters an imperative to hold a child’s body inviolate, as a means of preserving the ‘fiction’ of childhood innocence. As a result, such reluctance has produced a complete absence of case law in the UK to date - and consequently no judicial ‘test’ of the issue.

Child living organ donation therefore presents a fitting topic for a case study to explore the limits of child competence and to examine whether a procedure that can never be deemed to be *medically* in the best interests of the child, can and should nonetheless be ethically and legally justified. I will question whether current approaches within law and practice are able to justify child donation. Building on this I will then argue that by adopting an Ethics of Care approach, otherwise obscured but important relational considerations come to the fore that do indeed demonstrate that in certain circumstances child donation can and should be justified. I will begin with a critical examination of the state of the law and professional guidance relating to child organ donation, as it currently stands in the UK, with the addition of case law from the USA. The analysis will then be centred on a fictional scenario<sup>13</sup> involving 14-year old Ella, whose 18-month old son Thomas, is in urgent need of a kidney transplant.

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<sup>11</sup> Alison Diduck, *Law’s Families* (LexisNexis Butterworths 2003) 79.

<sup>12</sup> See Magi Sque and Dariusz Galasinski, “‘Keeping Her Whole’: Bereaved Families’ Accounts of Declining a Request for Organ Donation’ (2013) 22 *Cambridge Quarterly of Healthcare Ethics* 55

<sup>13</sup> This Scenario was adapted from one suggested by Dr Joe Brierley, Pediatric Intensivist at Great Ormond Street Hospital for Sick Children, London.

For various reasons of co-morbidity Thomas is not eligible for a deceased transplant and a living kidney donation from his mother Ella presents his best chance for survival.

Once Ella's case has been outlined I will apply the Ethics of Care framework to explore how in an extreme case such as hers, living organ donation by children can and should be justified. In particular I will place the notions of relational autonomy, psychological and emotional best interests, familial duty and sacrifice, and the social value of altruism within the care framework in order to establish that paediatric living organ donation is permissible not only as a measure of last resort to save a life but also in circumstances where quality of life is at stake. In addressing this I will again draw upon the three guidelines of the Ethics of Care framework, but in this chapter I will give special emphasis to Guideline Two - Consideration of the Child within their Past and Future Caring Relationships. Because the crucial issue in determining the 'right' course of action when using the Ethics of Care resides in the moral core of the strength of relationship, it will provide a new way of mitigating the tensions between donor, recipient and decision-maker that inevitably form part of the decision-making process when both parties are minors. It will also provide an apt method of testing how well a care framework works to evaluate best interests in a context where those interests are deemed to lie outside of the purely medical by upholding relational interests as outweighing any medical dis-benefits.

## **Section 1 - The Law and Organ Donation**

### **1.1 Legislation - The Human Tissue Act 2004 and Codes of Practice**

The current law as it relates to living organ donation is encapsulated in The Human Tissue Act 2004. The Act applies to England, Wales and Northern Ireland<sup>14</sup> and came into force in 2006. Although the Act repeals earlier legislation,<sup>15</sup> the laws relating to living organ donation remain much the same as under previous statutes. The remit of the 2004 Act as it applies to living organs, covers their storage and use, however the removal process remains governed by the common law.<sup>16</sup> Additionally much of the operation of the Act is subject to Regulations issued by the Secretary of State,<sup>17</sup> and its provisions are to be interpreted in accordance with nine Codes of Practice (CoP) issued by the regulatory authority created by the Act – the Human Tissue Authority. For our purposes the two most applicable codes are Code 1: Consent, and Code 2: Donation of Solid Organs for Transplantation.<sup>18</sup>

Section 33 of the Act provides that the removal or use of material from the body of a living person for the purpose of transplantation shall not be an offence if it is done in accordance with regulations issued by the Secretary of State. This includes that no reward is paid to the donor in return for the donation.<sup>19</sup> An important aspect of compliance is the ‘golden thread’<sup>20</sup> of provision by the donor of ‘appropriate consent’

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<sup>14</sup> Scotland has its own Act – Human Tissue (Scotland) Act 2006.

<sup>15</sup> Human Tissue Act 1961, Anatomy Act 1984, Human Organ Transplantation Act 1989.

<sup>16</sup> Human Tissue Authority, Code of Practice 2: Donation of Solid Organs for Transplantation (Version 14.0, Last Updated July 2014) Paragraph 32.

<sup>17</sup> The Human Tissue Act (Persons who lack Capacity to Consent and Transplants) Regulations (HT Act 2004 (PLCCT) Regs) 2006 (SI 2006/1659).

<sup>18</sup> Human Tissue Authority, Code of Practice 1: Consent (Version 14.0, Updated July 2014) and Code of Practice 2 (n21).

<sup>19</sup> HTA 2004 s33(1),(2), (3).

<sup>20</sup> Dr Ladyman, HC Standing Committee G Col 66, 27 January 2004 & Col 142, 29 Jan 2004.

<sup>21</sup> - a notion that Price claims is a ‘unifying theme’ of the legislation as a whole.<sup>22</sup>

Crucially ‘consent’ is not defined in terms of what is a valid consent, but rather in terms of who may give it. As this relates to living children, Section 2 states that the ‘appropriate consent’ would be the consent of the child himself. Whilst this section makes no mention of whether the validity of such consent is contingent upon the child being *Gillick* competent, Section 3 makes provision for incompetent children thereby implying the necessity of meeting the *Gillick* threshold for Section 2 to be applicable. This is clarified by CoP1, which states that a child aged 12 or over,<sup>23</sup> who is able to make their own decisions, may authorise donation of their organs,<sup>24</sup> and that the appropriate test to determine if they are competent to do so is that of *Gillick*.<sup>25</sup> This approach may be seen to be both restrictive and liberal at the same time. It is restrictive, at least in theory, in that by setting the bar in terms of chronological age it could be seen as undermining the spirit of the test as laid out in *Gillick*, which purposefully sets ‘sufficient maturity and intelligence’ and not age as the threshold. The CoP would therefore not countenance consent being given by an 11 year-old even though it might be possible under the *Gillick* test. However, in practice the stance in the CoP may be viewed as liberal, because as demonstrated by the systematic review of the case law in Chapter 3, it is evident that the courts hardly ever hold a child as young as 12 to be *Gillick* competent and certainly never for a procedure as serious as organ donation. Indeed, the stance taken in the Act and CoP appears to be at odds with, and therefore perhaps supersedes, the key and until recently sole, reference to

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<sup>21</sup> HTA 2004 s1(1).

<sup>22</sup> David Price, ‘The Human Tissue Act 2004’ (2005) 68 Modern Law Review 798, 805.

<sup>23</sup> The HTAu may have decided to be explicit about a lower age limit for the application of the *Gillick* competence test in response to professional concerns given during the consultation period for the CoP and Regulations over the lack of a minimum age. See Stephen Marks, ‘Should Children ever be Living Kidney Donors? – Editorial’ (2006) 10 Pediatric Transplantation 757, 759.

<sup>24</sup> COP 1 (n18) Paragraph 151.

<sup>25</sup> *ibid* Paragraph 152.

child living organ donation in English and Welsh case law - in the case of *Re W*.<sup>26</sup>

Here Lord Donaldson made the obiter statement that for a minor to be competent in such circumstances was ‘highly improbable’ as doctors would have to be satisfied that ‘the minor was “Gillick competent” in the context of so serious a procedure which could not benefit the minor’.<sup>27</sup>

It is possible to make the case that in the intervening 23 years since *Re W* the jurisprudence relating to child competence has moved on to such an extent that the courts might be prepared to find a minor child *Gillick* competent as envisioned by the Act.<sup>28</sup> Indeed in the 2015 case of *Re JM*, Mostyn J declares that the common law right to consent under *Gillick* *would* extend to the donation of blood or organs.<sup>29</sup> However in 1993 we see that the stance of the court was on Ethics of Care caution as expressed by Lord Donaldson in *Re W* when he noted that:

It is inconceivable that [the doctor] should proceed in reliance solely upon the consent of an underage patient, however “Gillick-competent”, in the absence of supporting parental consent and equally inconceivable that he should proceed in the absence of the patient’s consent.<sup>30</sup>

In contrast whilst CoP 1 maintains the importance of the kind of relational decision-making expressed by Lord Donaldson above, in noting that ‘even if the child is competent to consent, it is good practice to consult the person who has parental

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<sup>26</sup> (*a minor*)(*Medical Treatment: court’s jurisdiction*) [1993] Fam 64.

<sup>27</sup> *ibid* 79.

<sup>28</sup> See for example the case of *An NHS Trust v ABC & A Local Authority* [2014] EWHC 1445 (Fam) discussed in Chapter 3, where the court had a 13 year-old girl *Gillick* competent to consent to a termination of pregnancy.

<sup>29</sup> *Re JM (A Child)* [2015] EWHC 2832 (Fam) para 13.

<sup>30</sup> *Re W* (n26) 79.

responsibility for the child and to involve them in the process of the child making a decision', it is also clear that 'if the child is competent, the decision to consent must be the child's'.<sup>31</sup> Furthermore the Code stresses the necessity of protecting the child's confidentiality and states that disclosure of information should only be with the child's consent, plus the importance of guarding against the risk of undue influence to ensure that the child has consented to donation voluntarily.<sup>32</sup>

The Act also makes provision for children who are unable to give consent personally. Section 3 allows for those with parental responsibility to make the decision for the child in cases where first; the child is incompetent, or second; where he is competent but fails to make the decision.<sup>33</sup> This exercise of parental responsibility is subject to there being no prior decision of the child's to consent to, or refuse the procedure.<sup>34</sup> This raises the interesting question of whether the statute is making provision for a binding Advance Decision that would be able to override the exercise of parental responsibility, at least in the first category of the rare case where a previously competent child is, by intervening circumstances, subsequently rendered incompetent. If so, this would be in direct contradiction to the provisions of the Mental Capacity Act 2005 relating to Advance Decisions, which explicitly state that only competent persons aged over 18 can only make legally binding Advance Decisions.<sup>35</sup>

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<sup>31</sup> CoP1 Para 157.

<sup>32</sup> *ibid*

<sup>33</sup> HTA 2004 s2 (3)(c).

<sup>34</sup> HTA 2004, s2 (3)(b).

<sup>35</sup> MCA 2005 s24 (1)



## 1.2 - Approval Procedure for Child Living Organ Donors

The Human Tissue Authority (HTAu) oversees the operation of the Act. The Regulations set out that with the exception of domino donations,<sup>36</sup> the HTAu must approve all living organ donations for transplantation before the donation can take place.<sup>37</sup> For approval to be granted, the Regulations require that the Authority must be satisfied that no reward has or will be given, that consent for the purpose of transplantation has been given and that an Independent Assessor (IA) has conducted separate interviews with the donor (and if different from the donor, the person giving consent) and the recipient (or the person acting on behalf of the recipient) and submitted a report of their assessment to the HTAu.<sup>38</sup> This report must detail the information given to the donor regarding the procedure and risks, including the name and qualifications of the person supplying that information; the donor's capacity; any evidence of duress or coercion; evidence of offer of a reward; and any communication difficulties and how they were overcome.<sup>39</sup> CoP 2 stresses that although permissible under the Act, children are only to be considered as living donors in extremely rare circumstances<sup>40</sup> - although it gives no guidance on what these circumstances might be. Furthermore, in the case of child living organ donation, there are additional administrative safeguards in place with the requirement of a two-part approval process. Firstly, the approval of the Court must be obtained,<sup>41</sup> and second, only after

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<sup>36</sup> A domino donation is where a patient A is the recipient of a donation, for example a heart-lung cadaveric transplant from patient B, but who in turn is able to act simultaneously as a donor, by donating their functioning heart which had to be removed as part of the transplant process, to Patient C.

<sup>37</sup> CoP2 Para 35.

<sup>38</sup> CoP2 Para 36.

<sup>39</sup> *ibid* Para 37.

<sup>40</sup> *ibid* Para 49.

<sup>41</sup> *ibid* Para 49.

this has been obtained will the case go before the HTAu to be approved by a panel of three Authority members.<sup>42</sup>

### 1.3 - Professional Guidelines and Case Law

On a professional level, there are grave reservations around child living donors, with for instance the British Medical Association at one time stating that it is not appropriate for minors to donate non-regenerative tissue or organs.<sup>43</sup> Whilst there is a drive in the UK to increase the number of living kidney donors, with a 2014 Strategy Document asserting the intention to increase donation to ‘match world class performance’ by 2020, children as donors are conspicuous in their absence.<sup>44</sup> In contrast, Guidelines issued by a Joint Working Party of the British Transplantation Society and The Renal Society state that kidney donation by living children *can* be countenanced in ‘exceptionally rare circumstances’,<sup>45</sup> although as is the case with the Code for HTA, there is no elaboration on what these circumstances would be. However, the evident ethical tensions around autonomy and the validity of consent, provoke the Joint Working Party to declare that the ‘moral arguments for not subjecting under 18s to living kidney donation are compelling’.<sup>46</sup>

As noted above, there is no case law on child living organ donation in the UK. The closest case to have any bearing on the issue is the case of *Re Y*,<sup>47</sup> which has already

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<sup>42</sup> *ibid* Para 50.

<sup>43</sup> *Medical Ethics Today: It's Practice and Philosophy* (BMJ Books 1998).

<sup>44</sup> *Living Donor Kidney Transplantation 2020: A UK Strategy* (22 May 2014).

<sup>45</sup> Joint Working Party of The British Transplantation Society and The Renal Association, *United Kingdom Guidelines for Living Donor Kidney Transplantation* (3<sup>rd</sup> Edn, May 2011) 20.

<sup>46</sup> *ibid* 30.

<sup>47</sup> There is only one case that addresses bone marrow donation, and this involved an incompetent adult – see *Re Y (Mental Incapacity: Bone Marrow Transplant)* [1997] Fam 110.

been discussed in Chapter 3.<sup>48</sup> Taking a relational view of best interests, the court refused to consider the benefits to the recipient directly, but was prepared to consider the emotional benefits to Y of acting as a bone marrow donor. However as Elliston rightly notes, the low risk of donating bone marrow was a significant factor in the case and with the current approach of the courts to best interests, even allowing for a construction encompassing ‘emotional, psychological and social factors’, it would be unlikely to be sufficient to approve solid organ donation.<sup>49</sup> However, the most developed jurisprudence is found in the USA. In the absence of any UK case law, it will be instructive to examine the reasoning in the American cases, where over the course of more than 45 years the courts have, on rare occasions, permitted living children to donate an organ to a close relative.<sup>50</sup> The key lesson to be drawn from all of the US cases is that the decision to approve or decline authorization for donation in each case,<sup>51</sup> turns on the potential preservation of a close relationship and the psychological and social benefits which may come to the donor as a result.

The US index decision is that of the 1969 case of *Strunk v Strunk*.<sup>52</sup> Although the potential donor was not a child, but an adult with the mental age of a 6 year-old, the reasoning is analogous. He was chosen to donate a kidney to his brother who was critically ill. Even though the donor was unable to give valid consent, the Court held that it was in his best interests to donate in order to save his brother’s life. This case illustrates that best interests can be construed to include the psychological benefits of

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<sup>48</sup> Chapter 3, section 3.1

<sup>49</sup> Sarah Elliston, *The Best Interests of the Child in Healthcare* (Routledge-Cavendish 2007) 269.

<sup>50</sup> News Medical, ‘Legal, Ethical and Cultural Barriers to Child Organ Donations’ (8 September 2011) <[www.news-medical.net/news/20110908/legal-ethical-and-cultural-barriers-to-child-organ-donations.aspx7](http://www.news-medical.net/news/20110908/legal-ethical-and-cultural-barriers-to-child-organ-donations.aspx7)> < Accessed 8 March 2016>.

<sup>51</sup> UNOS data states that 96 living kidney donations were made by minor children between 1989-1998, as cited in Bryan Shartle, ‘Proposed Legislation for Safely Regulating the Increasing Number of Living Organ and Tissue Donations by Minors’ (2001) 61(2) Louisiana Law Review 433, 450.

<sup>52</sup> 445SW 2d145 (ky 1969)

being able to continue in a close relationship with the recipient as the justification for donating. Similarly, three years later the case of *Hart v Brown* came before the courts.<sup>53</sup> Following the reasoning of *Strunk* the court was satisfied that the psychological benefit to the 7 year-old donor of her identical twin sister's survival and continued companionship, justified the donation. However, an additional strand to the reasoning was the importance to the court placed on their satisfaction that the parents agonizing consideration of the situation indicated a lack of coercion. Similarly in the 1979 case of *Little v Little*,<sup>54</sup> the court held that the close relationship and the genuine concern for the other's welfare between a 14-year old girl with Down Syndrome and her younger brother, justified her donation of a kidney to him. Here the theme of altruism featured more strongly in the courts reasoning as it stressed that the girl's awareness of her brother's condition and the knowledge that she could help him were relevant factors, as were the acknowledgment that she understood loss and absence and would suffer psychologically from his death. It was held that whilst physical and psychological risks were minimal the psychological *benefits* were predicted to be substantial.

These cases can be contrasted with those where the court was not willing to authorize donation, and again it can be seen that these invariably turn on the absence of close relationship between donor and recipient. In the case of *In Re Richardson*,<sup>55</sup> it was held that a 17 year-old boy with the mental age of a 3/4 year-old should not donate a kidney to his 32 year-old sister despite being the most suitable donor. The lack of absolute medical necessity on the part of the recipient was a key consideration.

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<sup>53</sup> 289 A 2d 386 (Conn Sup Ct 1972)

<sup>54</sup> (1979) 576 SW 2d, Tex

<sup>55</sup> (1973) 284 So 2d 185 (La App 4<sup>th</sup> Cirt) 338.

Additionally, due to the bleak prognosis for the sister even if she were in receipt of a transplant, the courts rejected a relational argument that she could be a future carer for the boy. The court were also keen to emphasize the vital importance of defending the incompetent individuals right to ‘be free from bodily intrusion’ which it claimed was an ‘unqualified protection’ offered by the law. Equally in the 1975 case of *In Re Pescinski*,<sup>56</sup> the court held that it was not in the best interests of a 39 year-old man with the mental capacity of a 12 year-old to donate a kidney to his 38 year-old sister, due to lack of personal benefit to the donor coupled with his inability to consent. Shartle asserts that the best illustration of the courts’ reasoning in relation to the pivotal nature of relationships,<sup>57</sup> is in the case of *Curran v Bosze*.<sup>58</sup> This case involved potential bone marrow transplantation from 3 year-old twins to their 12 year-old half brother who was suffering with leukemia. Their father wanted the twins to undergo a blood test to determine their compatibility as bone marrow donors but the twins’ mother objected. The Court held that as there was not a close relationship between the children, with no evidence of the children being known to each other as family, it was not in the twins best interests to be considered as donors.

## **Section 2 - The case of Ella and Thomas**

In this section, I will outline the hypothetical scenario of Ella and her son Thomas. It was necessary to create a fictional scenario for this case study for a number of reasons. First, as noted above, no actual case concerning child organ donation has yet come before the UK courts. Secondly, it was imperative given the clinical reluctance to the practice, to construct a scenario that provided the optimum circumstances to

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<sup>56</sup> (1975) 226 NW2d 180 (Wis).

<sup>57</sup> Bryan Shartle, ‘Proposed Legislation for Safely Regulating the Increasing Number of Living Organ and Tissue Donations by Minors’ (2001) 61(2) Louisiana Law Review 433, 458.

<sup>58</sup> (1990) 566 NE 2d 1319 (Ill).

make a persuasive argument that child living organ donation was justifiable. Thirdly, the fictional case will act as a springboard to consider broader questions around the practice of child organ donation and urge new ways of thinking in order to countenance donation for quality of life as well as life-saving motivations.<sup>59</sup>

Ella, a 12-year-old girl, delivered a male infant at 32-weeks gestation, following a concealed pregnancy with no antenatal care. The infant, Thomas, was delivered in a toilet at home, wrapped and brought to the Emergency Department by the 12-year old with her mother, Julie. Thomas was resuscitated and transferred to the ICU where he clearly had multiple organ failure. After a few days organ support it had become clear that severe hypoxic injury to Thomas' brain had occurred, and that he also had kidney failure. The medical team discussed withdrawal of life-sustaining therapy in the infant's best interests as a possible option. Both Ella and her mother said they could not consider this; the grandmother citing her firm catholic faith and trust in God. ICU support was continued and eventually Thomas was weaned from mechanical support but had on-going renal dysfunction and a severe brain injury.

After several months, Thomas was discharged from hospital into the care of Julie and Ella. Julie went to court to obtain a Section 8 Child Arrangements Order that Thomas live with her and which bestowed upon Julie Parental Responsibility for Thomas, in addition to the Parental Responsibility already held for him by Ella. In the first year of life Thomas made very slow developmental progress and was diagnosed with severe spastic quadriplegic cerebral palsy. He required a

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<sup>59</sup> Arthur Caplan, 'A Quiet Revolution in Organ Transplants' (17 November 2015) Forbes <[www.Forbes.com/sites/arthurcaplan/2015/11/17/a-quiet-revolution-in-organ-transplants/](http://www.Forbes.com/sites/arthurcaplan/2015/11/17/a-quiet-revolution-in-organ-transplants/)> < accessed online 18 November 2015>.

gastrostomy to enable feeding, and although he did not require dialysis his kidney function never returned to normal and his weight gain was poor. By 18-months of age he had had two further intensive care admissions; one with a severe chest infection and one for a Nissen fundoplication to treat severe gastro-oesophageal reflux. Both were associated with worsening renal dysfunction, and now his kidneys were starting to fail.

Thomas was not listed for renal transplant because he fell outside current deceased donor listing due to his complex co-morbidity. His grandmother Julie had been diagnosed with pancreatic cancer and therefore could not donate, so the only potential related donor was his now 14-year-old mother, Ella. She has researched living donation on the Internet, had read of cases in other countries and had subsequently telephoned the Human Tissue Authority to ask for permission to donate a kidney to her son. Ella is completely fit and well, and her mother after some convincing is supportive of her daughter's desire to donate. Despite having a baby with complex needs, due to the support of her mother and the medical and nursing teams in the community, Ella has done well at school. However she has decided not to take any exams and rather focus on Thomas.

The hospital renal team is divided in their opinions on how to proceed. Some clinicians are of the view that whilst the current listing rules on deceased donor kidney donation are correct, as the entire team thinks Ella is clearly *Gillick*-competent, they ought to approach the HTA regarding her case. They have based their competence assessment on Ella's intelligence and understanding of the risks and benefits of the procedure, her articulate way of expressing her views, and her

mature attitude towards caring for her son. Others think that the sensible approach would be to opt for dialysis of Thomas until Ella is 16 and therefore presumed able to consent. The views of both the transplant surgeon and the senior renal doctor are that Thomas ought to be referred for palliative care. They cite as their grounds for this view - the lack of extended family support and the possibility that 14-year old Ella could resume a normal life when Thomas dies, although they do acknowledge that she may soon have to face the trauma of death of her mother, Julie, too.

These views raise the key themes in the case - respect for Ella's competence and autonomous choice, protection of her welfare as a child, and an assessment of her best interests. Each of these themes will be examined below, using the Ethics of Care Framework, and the strength of these arguments measured against care's aim of maintaining and nurturing the relationships that are important in Ella's life.

### **Section 3 - Applying Guideline One: *Attentiveness to the Interconnected Individual Child in her Particular Circumstances* - Is Ella Competent to Consent and is Consent Enough?**

#### **3.1 - Gillick Competence and Ella's Expertise**

Dwyer and Vig claim that under a standard justificatory model, informed consent is seen as the 'first and best' ground for permitting a person to take risks with their health for the benefit of another.<sup>60</sup> Equally they are correct in noting that this model

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<sup>60</sup> James Dwyer & Elizabeth Vig, 'Rethinking Transplantation between Siblings' (1995) 25(5) Hastings Cent Rep 7.



does not work when concerned with young children who lack decisional capacity.<sup>61</sup> However, for children in mid-childhood, such as Ella, there *is* the potential to give competent informed consent and one of the most striking facts of her case is that despite their divergence of opinion, the entire renal team thinks that Ella is clearly *Gillick* competent. However, if the clinicians wished to pursue the possibility of donation, then both the Court and the HTAu would also have to be persuaded of the question of Ella's competence.<sup>62</sup> As seen in the systematic case review in Chapter 3, the courts are highly reluctant to find a child as young as Ella to be *Gillick* competent, and this is particularly so regarding serious or non-therapeutic procedures – of which living organ donation is both. However, I am not persuaded by Lord Donaldson's stance in *Re W*<sup>63</sup> that the decision to donate an organ is of such fundamental difference in quality to other healthcare decisions that it is highly improbable that any child under the age of 18 would ever be competent to consent to it. As I have argued elsewhere, the courts have recently shown a 'return to the test for competence as it was initially framed in *Gillick*'<sup>64</sup> in the case of *An NHS Trust v ABC and A Local Authority*.<sup>65</sup> The case, which held that a 13-year-old girl was competent to consent to be termination of pregnancy, demonstrated that 'despite academic disquiet over the theoretical coherence of *Gillick* and past judicial reticence about practically applying it, a test for competence can be constructed wherein children as young as 13 can meet the criteria'.<sup>66</sup> Although the decision in question in that case was different in nature to organ donation, it was nonetheless a serious procedure involving an invasion of the bodily integrity of a child younger than Ella, and one that may potentially have lasting

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<sup>61</sup> *ibid*

<sup>62</sup> See section 1.2 above.

<sup>63</sup> See section 1.1 above.

<sup>64</sup> Kirsty Moreton, '*Gillick* Reinstated: Judging Mid-Childhood Competence in Healthcare Law: *An NHS Trust v ABC & A Local Authority* [2014] 23(2) Medical Law Review 303, 307.

<sup>65</sup> [2014] EWHC 1445 (Fam).

<sup>66</sup> Moreton (n64) 304.

implications both physically and psychologically. Therefore acting on the presumption that it is *possible* for the courts and the HTAu to find Ella competent to consent to donate her kidney, it is imperative to take a particularist approach to identify the factors in her individual case that would point to her competence.

Using the Ethics of Care framework, Guideline One would prompt a consideration of the child's individual circumstances and personal expertise arising from her life experiences and interconnected relationships,<sup>67</sup> as vital factors in assessing competence. In Ella's case, the fact that she became pregnant at a very young age and concealed her pregnancy may be a factor that increases her vulnerability, as discussed in section 4.2 below. However, she chose to keep and raise Thomas and has evidently become a dedicated mother to him. Ella's choice is perhaps evidence of her maturity, strength and ability to think through the implications for her own life even in the most difficult of circumstances. The assumption, from the age of 12, of the responsibility of practical daily care of her child, will have enabled Ella to develop a 'distinctive way of thinking'.<sup>68</sup> This 'maternal thinking' as posited by Ruddick, and discussed in Chapter 1,<sup>69</sup> allows for reason to be shaped by the key care theory notions of the love and responsibility, rather than abstract objectivity and emotional detachment.

The care that Ella has provided for Thomas would have surpassed that usually required in mothering, due to his severe disabilities. This alone would place Ella in a completely different position in terms of understanding and maturity to the typical 14-year-old girl. Add to this the insights gained from dealing with the emotional and

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<sup>67</sup> Jennifer Nedelsky, *Laws Relations: A Relational Theory of Self, Autonomy and Law* (OUP 2012).

<sup>68</sup> Sara Ruddick, *Maternal Thinking: Toward a Politics of Peace* (Ballantine Books 1989) 61.

<sup>69</sup> See Section 1.2.2

psychological impact of Thomas's intensive care admissions and worsening prognosis over the past 18 months, and, I argue, Ella's drive to achieve Ruddick's 'first goal of mothering' – preservation and protection,<sup>70</sup> would have been heightened. Ruddick would argue that an important aspect of protective love is to identify as 'natural' what is 'given' and this includes the body that the child inhabits.<sup>71</sup> Whilst in Thomas's case this is a severely disabled and failing body, Ruddick is also right that this identification of the natural with the given 'does not mean that protecting mothers accept whatever is natural. Mothers fight their babies diseases (...)'.<sup>72</sup> Indeed Ruddick's profound statement that 'mothers might be said to negotiate with nature on behalf of love', may be borne out by the empirical evidence from a German study, which shows that mothers were found to be the most frequent donors.<sup>73</sup> The study attributed the apparent gender imbalance in living donation to men's greater earning capacity and the impact on this of recuperation after surgery, plus their ability to better resist familial pressure. However, whilst none of these gender-based tensions are evident in Ella's case, there is the possibility, albeit slim, that her desire to donate may be driven not by her 'maternal thinking' but rather as a response to feminine gender expectations of self-sacrifice being an essential facet of motherhood.

Additionally, Ella's maturity, understanding and intelligence is demonstrated by the fact that she took the initiative to research the possibility of living kidney donation and to presumably inform herself of the nature, risks and benefits of the procedure. She then took the proactive, and bold, step of contacting the HTAu of her own accord,

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<sup>70</sup> Ruddick (n68) 70.

<sup>71</sup> *ibid* 76.

<sup>72</sup> *ibid*

<sup>73</sup> N Biller-Andone, 'Gender Imbalance in Living Organ Donation' (2002) 5 *Medicine, Health Care and Philosophy* 199, 201. The study showed that 27 % of donors were mothers.

apparently without any pressure or indeed encouragement from anyone else. A vital aspect of a modern assessment of child competence, as demonstrated in *ABC*, is a ‘pragmatic recognition of children’s increased ability to access information relevant to the decision via modern technology’,<sup>74</sup> and this combined with the fostering of an environment in accordance with children’s participatory rights as outlined in Article 12 UNCRC, means that children are more willing and able to share their viewpoint. However, the mere fact of access to information does not mean that consent is properly informed even if the child is competent. Indeed, there is a danger that Ella’s decision may be one which is not informed by a careful consideration of the benefits and risks but rather by a desperate desire to save her son’s life. Caplan identifies the environmental pressures that surround living donation as having a negating effect on the notion of true voluntary consent in this context, as ‘the realization that one could be blamed for the failure to help a (...) child may be so frightening that potential donors see themselves as having no choice’.<sup>75</sup> This concern is amplified as evidence indicates that, even for competent adults, the provision of sufficient information to produce a valid consent is irrelevant, as ‘disclosure of risks frequently has no effect on the decision to donate’ which is viewed as ‘automatic’.<sup>76</sup> These pressures may be multiplied in the case of child donors, where Garwood-Gowers observes that information and voluntariness may also be subsumed in the child being unduly eager to donate in a bid to appear mature.<sup>77</sup> Even if this is the case however, I am not convinced that this undermines her competence, as people give consent in other

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<sup>74</sup> *ABC* (n28)

<sup>75</sup> Arthur Caplan, ‘Am I my Brother’s Keeper?’ (1993) 27 *Suffolk University Law Review* 1195.

<sup>76</sup> Ryan Sauder and Lisa Parker, ‘Autonomy’s Limits: Living Donation and Health-Related Harm’ (2001) 10 *Cambridge Quarterly of Healthcare Ethics* 399, 403.

<sup>77</sup> Austen Garwood-Gowers, *Living Donor Organ Transplantation: Key Legal and Ethical Issues* (Ashgate 1999) 147, fn 654 – as noted in a study by R G Simmons et al, *Gift of Life* (1977 Wiley & Sons) 177, where it was found that 6 out of 26 adolescent donors in a Minnesota study donated on this basis.

desperate situations,<sup>78</sup> where their consent is ‘informed’ by weightier relational concerns. Further, the assessment mechanisms employed before the HTAu would be prepared to authorise donation, should be adequate to uncover and remedy any deficits in information.

### 3.2 - Ella’s Vulnerability – a Positive or Negative Factor in the Competence Assessment?

As discussed in Chapter 1, Martha Fineman’s assertion that vulnerability is an ‘enduring aspect’ of the human condition,<sup>79</sup> is a vital part of the consideration of the individual interconnected child and within this Guideline operates on three levels.<sup>80</sup> On the primary level rooted in the fact of embodiment,<sup>81</sup> Ella is vulnerable to the uncontrollable risks of physical harm that are inherent in living donation. It is arguable that given a child’s limited life experience or ability to understand the real nature of these risks, that no child should be exposed to them without a corresponding, direct personal physical benefit.<sup>82</sup> Whilst it is true that Ella is fit and well and therefore these risks would be low, in the context of living organ donation there is no *physical* benefit to her that would correspond with even such low risks. This inability to mitigate vulnerability by direct personal gain could then become a barrier to declaring a child competent. However the Ethics of Care would reject such a view as unjustifiable ‘egocentric reasoning’.<sup>83</sup>

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<sup>78</sup> Stanford Encyclopedia of Philosophy, ‘The Donation of Human Organs’ (28 Oct 2011).

<sup>79</sup> Martha Albertson Fineman, ‘The Vulnerable Subject: Anchoring Equality in Human Condition’ [2008] 20 Yale Journal of Law and Feminism 1, 8.

<sup>80</sup> See Chapter 2, Section 4.2.1

<sup>81</sup> Fineman, (n79) 9.

<sup>82</sup> Joe Brierley and Vic Larcher, ‘Organ Donation from Children: Time for Legal, Ethical and Cultural Change’ (2011) 100 Acta Paediatrica 1175, 1177.

<sup>83</sup> Dwyer (n60) 9.

Secondly, and presenting greater difficulty for a competence assessment, is the vulnerability that arises as a result of living in relationships and the emotional interconnectedness that produces. Ella is exposed on a psychological level. Here the balance will be sought between those vulnerabilities which might nonetheless point in favour of donation, such as the desire to protect borne out of preservative love discussed above, and those against such as risks to the child's psychological 'wellness'. These risks may manifest themselves as guilt or regret if the transplant is unsuccessful,<sup>84</sup> or from familial disapproval should she choose not to donate. For some commentators that in itself is reason enough to justify a blanket legal prohibition on paediatric organ donation.<sup>85</sup> Another potential source of psychological vulnerability, even in the event of a successful transplant, is a feeling of neglect or lack of appreciation if the focus is on the recipient rather than the donor.<sup>86</sup> In Ella's case she has the additional risk that this vulnerability may take the form of guilt or shame in failing to seek antenatal care and potential responsibility for Thomas's subsequent prematurity and resulting disabilities, which might bring into question whether her decision is actually a competent one underlined by maturity and understanding or is indeed a means of soothing her conscience.

However, concerns over vulnerabilities at levels one and two may, in Ella's case, be mitigated by the benefits found at level three and therefore I am not convinced by Marks' argument that the elimination of guilt is a sufficient reason to justify a blanket ban on donation.<sup>87</sup> At this final level of vulnerability is found that which is necessary in order to truly flourish in relationships; the notion of surrender to another person. It

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<sup>84</sup> Shartle (n57) 467.

<sup>85</sup> Marks (n9) 758.

<sup>86</sup> Nils Brockx, 'Living Organ Donation & Minors: A Major Dilemma' (2013) 20(1) Eur J Health Law 41, 54.

<sup>87</sup> Marks (n9) 758.

is on this most subtle level, that an Ethics of Care approach is particularly adept at seeking to uncover that which is of the most value morally. Just as in any human relationship there are ambiguities and contradictions,<sup>88</sup> and none more so than in the maternal-child relationship. This would evidently be the case in the relationship between Ella and Thomas. There may remain the nagging doubt over whether she really wished to keep Thomas at all, given that her not seeking an abortion may have been more as a result of denial at her situation than conscious choice. This potentially may act to undermine some of the presumptions upon which the assessment competence is being based on.

Nonetheless her willing adoption of her maternal responsibilities in the intervening 18 months indicates a deep and genuine relationship between them, which surely cannot be dismissed by the promise of a ‘normal life’ should Thomas be allowed to die, as some of the clinicians suggest. Rather, I contend that whether her motivation be to assuage guilt, however misplaced; to avoid further trauma in a bid that “something good come out of something bad”; or even to live up to the expectation of maternal duty – that these vulnerabilities are to be celebrated and recognized as the essence of care which can provide the courage to do extraordinary things, just as Ella is seeking to do for Thomas.

### 3.3 - The Embodied Experience of the Organ Donor

A third factor under Guideline One, which would aid in a fuller assessment of Ella’s competence is an understanding of the embodied reality of the decision. One of the objections to paediatric living organ donation, is concern over the serious invasion of

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<sup>88</sup> Ruddick (n68) 68.

the child's bodily integrity. As Garwood-Gowers notes, 'it is obviously a very serious business to open up anyone and take an organ out of them for donation. It must be considerably more serious, both psychologically and physiologically, when that person is a young child'.<sup>89</sup> Such being the case, I concur with Broeckx's assertion that 'when privacy and physical integrity are involved, it is more important than ever to closely align the law with reality'.<sup>90</sup> Indeed in Ella's case the reality of her life experience places her in a different position to that of an 'average' 14-year-old girl and accordingly the assessment of her competence should reflect this. She has already experienced the profound 'conjoined embodiment' of pregnancy,<sup>91</sup> and the bodily sacrifice of childbirth. As his mother, Ella not only has an intimate emotional connection with Thomas, arising from 'maternal thinking', but a physical one too. She has literally given of her body to bring him into the world and continues to give of her bodily effort to care for his complex bodily needs. As Ruddick notes, in myriad ways children's bodies, in all their distinctiveness, 'assert themselves: this physical being is here; whoever deals with me deals with my body'.<sup>92</sup> In this sense it may be viewed as a natural extension of Ella's bodily sacrifice that she desires to donate another part of her body to his body – one that her body created. Whilst recognizing Thomas's bodily nature, she is using the resources at her disposal, even her own body to seek to confront his limitations, much as Ruddick contends that 'nature can be thought of as a respected opponent with whom they [mothers] are watchfully and sometimes antagonistically engaged'.<sup>93</sup>

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<sup>89</sup> Garwood-Gowers (n77)143.

<sup>90</sup> Brockx (n86) 46.

<sup>91</sup> Marie Fox and Kirsty Moreton, '*Re MB (An Adult: Medical Treatment)* and *St George's Healthcare NHS Trust v S: The Dilemma of the Court-Ordered Caesarean*' in Jonathan Herring and Jesse Wall (eds) *Landmark Cases in Medical Law* (Hart Publishing 2015).

<sup>92</sup> Ruddick (n68)76.

<sup>93</sup> *ibid* 77.



Furthermore, allowing Ella to choose for herself whether or not to donate a part of her body to another acknowledges the ‘deeply personal’ nature of the potential procedure. It also reflects her interest in her own bodily integrity, and respects the notion that in mid-childhood, emotional connection to bodily experience and the impact of the body upon individual self-identity become increasingly important.

### 3.4- The Limits of Autonomy – is Consent enough?

As the entire renal team believe that Ella is *Gillick* competent to consent to donating her kidney to her son, and a compelling case can be made for that belief so as to persuade the court and the HTAu on the basis of the factors discussed above, then I contend that her consent *should* be sufficient. For Garwood-Gowers a prohibition on child living organ donation whether in theory by a legislative ban or in practice by self-restriction on the part of the medical profession, as appears to be the case in England and Wales, would be to ‘interfere with their [children’s] self-determination too much’.<sup>94</sup> I agree.

Yet, despite this, many of the clinicians in Ella’s case do not believe that respect for her competent autonomous wish *is* a sufficient basis for permitting the donation to go ahead.<sup>95</sup> For adults to become a living organ donor, competent, informed and voluntary consent would certainly be sufficient and it can be questioned whether there is any ‘moral difference’ between a child acting as a donor as opposed to an adult.<sup>96</sup> As Webb and Fortune ponder ‘should a fully competent 15-year-old not be afforded the same status as their 23-year-old relative? If both are willing to donate, should

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<sup>94</sup> Garwood-Gowers (n77)144.

<sup>95</sup> Stanford (n78).

<sup>96</sup> Nicholas JA Webb and Peter-Marc Fortune, ‘Should Children ever be Living Kidney Donors?’ (2006) 10 *Pediatr Transplantation* 851, 854.

clinical factors alone dictate the rightful donor?’<sup>97</sup> Indeed even with the courts strict interpretation of *Gillick*, once the threshold is reached they are usually amenable to allowing a child to *consent* to, if not refuse, the proposed procedure. The judgment in *ABC* is to be applauded for its unambiguous stance on the determinative impact of a finding of child competence, summed up in the assertion by Mostyn J that ‘if I am to determine that A does have sufficient understanding and intelligence to know what a termination would involve, then that is the end of the matter’.<sup>98</sup>

One possible explanation is that the procedure does not fall within the definition of medical ‘treatment’ and is not in the child’s best *medical* interests and therefore should be treated as a special case. Hagger notes that even in the case of competent children potential restrictions also apply.<sup>99</sup> This is not entirely convincing though, as there are other similar scenarios, such as medical research where competent children are permitted to give their consent, and by treating living organ donation as a separate class it is unjustifiably privileging medical interests over other, perhaps more important relational, social, and emotional interests. If however, we accept that the competent child’s consent is a necessary but not sufficient condition, then there would need to be additional requirement(s) to reach the sufficiency threshold. Webb and Fortune suggest that one such requirement would be the agreement of those with parental responsibility, who would also be required to demonstrate that their reasoning for wishing to proceed with the donation was consistent with that of the child.<sup>100</sup> Another requirement seen in the US guidelines is that the child should be the

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<sup>97</sup> *ibid* 855.

<sup>98</sup> *ABC* (n28) Para 9.

<sup>99</sup> Lynn Hagger, *The Child as Vulnerable Patient: Protection and Empowerment* (Ashgate Publishing 2009) 5.

<sup>100</sup> Webb (n95) 855.

only possible source of the organ.<sup>101</sup> This would not be a problem in Ella's case as she is indeed the only source, however it is difficult to justify why this additional requirement is necessary, as to do so appears to undermine the arguments for why they can donate in the absence of an alternative donor.<sup>102</sup> Finally, an oft-positated requirement would be to demonstrate that the procedure is also in the best interests (broadly interpreted) of the child. This stands in stark contrast to Mostyn J's reading of the relationship between *Gillick* competence and best interests in *ABC*, where he noted that if the child reached the required threshold, then she could lawfully make a decision 'even if the result of that would lead her to take steps which are wholly contrary to her best interests'.<sup>103</sup> Nonetheless, in section 5, we will go on to explore the case for how living donation could be shown to be in both Ella's and Thomas's best interests.

## **Section 4 - Applying Guideline Two : *Consideration of the Child's***

### **Past and Future Caring Relationships - What are Ella's and Thomas's Best Interests?**

#### **4.1 Broad Interpretation of Best Interests**

As noted above, best interests may come into play in two ways here. First, even if Ella were *Gillick* competent, it might be necessary to demonstrate that to donate her kidney is also in her best interests. Secondly, if the courts or the HTAu were not convinced that Ella was competent then the decision, in accordance with the Children

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<sup>101</sup> See, Counsel on Ethical and Judicial Affairs, *The Use of Minors as Organ and Tissue Donors* (American Medical Association 1993); The Authors for the Live Organ Donation Consensus Group, *Consensus Statement on the Live Organ Donor* (2000) 282 J Am Med Assoc 2919.

<sup>102</sup> Webb (n95) 855.

<sup>103</sup> *ibid*

Act 1989, would be taken with the child's welfare as the paramount consideration.<sup>104</sup>

Ella's mother Julie, as the person with parental responsibility for Ella could provide that consent, although it is most likely that Ella would be made a ward of court in this scenario. However, because the recipient Thomas is Julie's grandson, for whom she has also acquired parental responsibility, there may be a conflict of interest here.

Therefore the question arises, whose interests take precedence – Ella's or Thomas's and in fact are their interests even in conflict at all. The case of *Birmingham City Council v H*,<sup>105</sup> involved the competing interests of a minor mother and her baby, both of whom were in the care of the state. The court held that the interests of the child who was the subject of the application – here the baby, should be paramount, although Bainham has rightly perceived that it seems unjust that the interests of one child should be preferred over the other merely because they are technically the subject of the application.<sup>106</sup>

Under Guideline Two the child is to be considered in the context of her past and future caring relationships, which would include all the individual connections between Julie, Ella and Thomas plus a picture of the family in a holistic sense. Crouch and Elliott contend that in the US case law the courts have been prepared to interpret best interests 'as broadly as necessary in order to help the patient and her family'.<sup>107</sup> In a position such as Julie's, Bainham and Gilmore query whether parents are bound to act *only* in the best interests of the child is relevant.<sup>108</sup> They contend that whilst it is debatable that there may be some scope for consideration of interests outside those of

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<sup>104</sup> S1 CA 1989.

<sup>105</sup> (*A Minor*) [1994] 1 2 AC 212 HL.

<sup>106</sup> Andrew Bainham, 'The Nuances of Welfare' [1995] CLJ 512.

<sup>107</sup> Robert Crouch and Carl Elliott, 'Moral Agency and the Family: The Case of Living Related Organ Transplantation' (1999) 8 Cambridge Quarterly of Healthcare Ethics 275, 280.

<sup>108</sup> Andrew Bainham and Stephen Gilmore, *Children: The Modern Law* (4<sup>th</sup> edn, Family Law, Jordan Publishing Ltd, 2013) 349.

the individual child that parents may not consent to a procedure that is obviously to the *detriment* of the child.<sup>109</sup> In terms of establishing best interests, the US case law turned on the impact of relationships and the psychological and social benefits that donation can bring. In *Shrunk* the court came to their decision to approve the donation by balancing the medical risks of donating against the psychological risks of being forbidden to donate and declared that the donor's 'well-being would be jeopardized more severely by the loss of his brother than the removal of a kidney'.<sup>110</sup> A more encompassing theme of the benefit of a complete and stable family environment was a key factor in *Hart*, where the evidence of the psychiatrist to the court was that

if the expected successful results are achieved they would be of immense benefit to the donor, in that the donor would be better off in a family that was happy than in a family that was distressed and in that it would be a very great loss to the donor if the donee were to die from her illness.<sup>111</sup>

In terms of assessing psychological benefits, Garwood-Gowers notes that '(...) there must surely be cases where the physical harm and jeopardy to the minor are outweighed by the prospective psychological benefit from donating'.<sup>112</sup> He suggests three criteria that should be addressed when considering if donation is in a child's best interests; first, that the prospective harm to the donor must be low and indeed exceeded by the prospective benefit.<sup>113</sup> For Ella, it has already been established that the medical risks are low and the potential benefits could be high. She may heroically

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<sup>109</sup> *ibid* 350.

<sup>110</sup> *Shrunk* (n52) 146.

<sup>111</sup> *Hart* (n53) 389.

<sup>112</sup> Garwood-Gowers (n77)141.

<sup>113</sup> *ibid* 146.

save the life of her son<sup>114</sup> and enjoy an ongoing relationship with him. This in turn may help to assuage potential guilt over her choices in pregnancy and help her to produce ‘something good’ in a difficult situation. In relation to this, Jackson notes that most studies show that donors experience increased self-esteem and feelings of well-being.<sup>115</sup> Shartle asserts that benefits could be accrued, not merely immediate.<sup>116</sup> For Ella, the act of donation may provide peace of mind to her dying mother Julie, which in turn could comfort Ella when dealing with her grief. This lines up with Zinner’s claim that ‘a psychological (emotional, social) benefit may prove as valuable to one’s mental health as therapeutic benefits to one’s physical health’.<sup>117</sup>

Garwood-Gower’s second criterion is that the donation must be by a substantial distance the best option for the recipient. With Thomas’s co-morbidities, it appears that donation by Ella is his only option, barring the suggestion of dialysis as suggested by some of the clinicians. Although it is possible to survive for some time on dialysis, Thomas has not undergone the procedure in the past so presumably there is uncertainty as to its effectiveness in his case and in any event it would have a clear impact on his and therefore Ella’s quality of life. The third criterion is that the donor must have some direct interest in the recipient’s well-being.<sup>118</sup> Ella, as Thomas’s mother probably has the strongest relational case for a direct interest in his well-being, and as Broeckx notes the benefit here would lie ‘mainly in the prevention of

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<sup>114</sup> L Friedman Ross and R Thistlethwaite, ‘Minors as Living Solid-Organ Donors’ (2008) 122(2) *Pediatrics* 454, 455.

<sup>115</sup> Emily Jackson, *Medical law: Text, Cases and Materials* (3<sup>rd</sup> edn, OUP 2013) 604 – citing RG Simmons et al, *Gift of Life: The Social and Psychological Impact of Organ Transplantation* (Wiley 1977).

<sup>116</sup> Shartle (n57) 467.

<sup>117</sup> Susan Zinner ‘Cognitive Development and Pediatric Consent to Organ Donation’ (2004) 13 *Cambridge Quarterly of Healthcare Ethics* 125.

<sup>118</sup> Garwood-Gowers (n77) 146.

emotional pain'.<sup>119</sup> The benefit may manifest itself in heightened self-esteem at the joy of being able to secure a complete, happy family.<sup>120</sup> The court in *Little* recognized both the individual benefits of altruism in promoting personal growth, even in children, and the wider social benefits of applauding an altruistic mindset, declaring that:

Studies of persons who have donated kidneys reveal resulting positive benefits such as heightened self-esteem, enhanced status in the family, renewed meaning in life, and other positive feelings including transcendental or peak experiences flowing from their gift of life to another.<sup>121</sup>

On a practical level, both because of his young age and his potential life long need for care due to his disabilities, her life is heavily invested and intertwined with his.

#### 4.2 - Relational Obligation

An alternative argument that fits in well with the care framework is put forward by Dwyer and Vig, who justify child living organ donation on the basis of relational obligation.<sup>122</sup> They contend that to seek to shoehorn psychological benefits into some form of self-interested best interest is 'egocentric constraint'.<sup>123</sup> Rather, a feature of a child's responsibility as a member of a family is to help those with whom she shares an intimate relationship, as noted in Chapter 1, under the Ethics of Care the child can also become the 'one –caring'. Crouch and Elliott note Feinberg's categorization of

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<sup>119</sup> Broeckx (n86) 51.

<sup>120</sup> *ibid*

<sup>121</sup> *Little* (n54) 449.

<sup>122</sup> James Dwyer & Elizabeth Vig, 'Rethinking Transplantation between Siblings' (1995) 25(5) *Hastings Cent Rep* 7.

<sup>123</sup> *ibid* 8.

‘self-regarding interests’ and ‘other-regarding interests’<sup>124</sup> and define the latter as ‘desires that an agent has for the well-being of another person’.<sup>125</sup> As Herring and Foster contend, under an Ethics of Care view a patient ‘necessarily has obligations to those whom she relates (...) Thus acting morally towards others is a central part of ensuring her own best interests’.<sup>126</sup> One aspect of this obligation concerns ownership of the body. There is some controversy over whether an individual owns their own body,<sup>127</sup> and it certainly does not follow that the rest of the family have any claim on it. If Julie were to consent to Ella acting as a donor for Thomas, Lyons argues that this would be on the basis of a propriety interest in Ella’s body.<sup>128</sup> The rationale for this is that neither Ella nor her kidney would exist but for Julie’s reproductive labour, which therefore legitimizes the ‘redistribution of [her] biological wealth’.<sup>129</sup>

Immediate questions arise over risk of familial pressure or coercion, particularly if the evident benefits are solely to the recipient, or even society as a whole in terms of preservation of resources.<sup>130</sup> Certainly, this ‘duty’ should never translate into a utilitarian obligation to use one’s body to rescue another. Indeed the idea of compulsion is repugnant as vividly expressed in the US case of *McFall v Shimp*:

For a society which respects the rights of one individual, to sink its teeth into the jugular vein or neck of one of its members and suck from it sustenance for another member, is revolting to our hard-wrought concepts of jurisprudence.

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<sup>124</sup> Joel Feinberg, *Harm to Others. Volume I: The Moral Limits of the Criminal Law* (OUP 1984) 70.

<sup>125</sup> Crouch (n166) 280.

<sup>126</sup> Jonathan Herring and Charles Foster, ‘Welfare means Relationality, Virtue and Altruism’ (2012) 32 *Legal Studies* 480.

<sup>127</sup> Barry Lyons, ‘The Good that is Interred in their Bones: Are there Property Rights in the Child?’ (2011) 19(3) *Medical Law Review* 372, 380.

<sup>128</sup> *ibid* 374.

<sup>129</sup> *ibid* 372.

<sup>130</sup> Broeckx (n86) 54.



Forceable extraction of living body tissues causes revulsion to the judicial mind.<sup>131</sup>

Lyons questions the strength of Dwyer and Vig's model of obligation, claiming that it fails because it is based on confusion between the separate notions of being 'under an obligation' and 'being obliged'.<sup>132</sup> I am unconvinced that this is anything more than semantics. I am persuaded by Dwyer and Vig's assertion that moral obligations do exist in families and that the strongest duty rests on parents, a lesser duty on siblings and a slight (if any) duty on strangers.<sup>133</sup> This contention clearly aligns with Noddings circles and chains conception of the priority of care, discussed in Chapter 1, where she claims that partiality underpins the directive to care and that we should owe the most to those who are closest to us. This is of particular note in Ella's case as she is both parent, and in a real sense sibling, so it is most likely that duty to her life experiences she owes the stronger parental duty despite being a minor herself. If this is the case then even in absence of external pressure, there remains in this 'duty', a pressure constructed and 'self-inflicted' by the child themselves by their own emotional ties and conscience. As explained by Crouch and Elliott here 'the more conventional image of coercion as a threat by another agent is turned inward'.<sup>134</sup> But in response, I concur with Crouch and Elliott that the suggestion of relational duty as impinging on voluntariness of choice should be resisted as:

We must recognize that moral and emotional commitments are not exceptional, are not constraints on freedom, but rather a part of ordinary

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<sup>131</sup> 10 Pa D&C 3d 90 (pa 1978).

<sup>132</sup> Barry Lyons 'Obliging Children' (2011) 19(1) Medical Law Review 55, 59.

<sup>133</sup> Dwyer (n60) 11.

<sup>134</sup> Crouch (n166) 276.

human life. More specifically, they are part of ordinary family life that we must take seriously if we want to understand how family members can make free choices about organ donation.<sup>135</sup>

Linking this back to the desire to preserve and protect, Ruddick reflects that ‘many mothers (...) remember a specific appreciation of the overwhelming obligation that preservative love presumes’.<sup>136</sup> Whilst it is clear that Thomas’s interests in survival and quality of life are also, in an instrumental sense, Ella’s interests by virtue of the relationship she shares with him, they may also be acting because these things are important to Thomas in and of itself. For example, if Thomas were subsequently taken into state care and Ella was unable to have a relationship with him, she may nonetheless desire to donate because survival is important to Thomas himself.

#### 4.3 - Importance of Past and Future care

An important element of the consideration of relationships under Guideline Two is to place them in the context of past and future care. Clearly Ella has been the recipient of quality care in the past, both from her mother Julie and from health and social care workers in the community, which have enabled her to care for Thomas and to be successful in her education. However, with Julie being diagnosed with pancreatic cancer, which has a survival rate at 1 year of just 20%,<sup>137</sup> the likelihood is that Ella will not have that maternal source of support available to her in the months and years following the donation. The theme of future care featured heavily in the US case of *Curran* and the absence of any real past or future emotional bond between donor(s)

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<sup>135</sup> *ibid* 278.

<sup>136</sup> Ruddick (n68)70.

<sup>137</sup> Cancer Research UK, Pancreatic Cancer <[www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/pancreatic-cancer/survival](http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/pancreatic-cancer/survival)> Last accessed 27 March 2016.

and recipient, even in the presence of biological connection, was the main reason that the court withheld authorization in *Curran*.<sup>138</sup> The second of the three factors outlined in the case as necessary in order to approve bone marrow donation (and therefore arguably even more important in the case of solid organ donation) was the assurance of future emotional support available to the child from their primary carer. The court felt that this was lacking in this case as the mother objected to the procedure and so could not be relied upon to offer constant reassurance and support and as the father's contact was limited to periodic visitation it would not be available on his part either.<sup>139</sup>

In Ella's case, the fear as expressed by some clinicians in the renal team, is that Ella will be unable to cope with recovering from major surgery and take care of Thomas's needs, both short and long-term, post donation, whilst dealing with the failing health and ultimately bereavement of her mother. In the worst case, such a situation could lead to Ella and Thomas being separated and taken into the care of the State. In such a situation, where future care may be lacking, Shartle would caution against the child proceeding to donate, as he contends that emotional support is key to allay fears or concerns over what may be a frightening procedure.<sup>140</sup> Furthermore, Ella's desire to focus on a long-term commitment to care for Thomas would be at the expense of her education and could severely impact upon her life goals and opportunities. It is interesting that in Ella's case it is the most experienced clinicians – the transplant surgeon and senior renal doctor that have the strongest objections to her acting as a donor and feel that it would be in Ella's best interests for Thomas to receive palliative

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<sup>138</sup> *Curran* (n58)

<sup>139</sup> *ibid*

<sup>140</sup> Shartle (n57) 468.

care and to die ‘naturally’. Whilst on the face of it this may be seen as a compassionate stance, the demise of Thomas would increase not lessen Ella’s psychological burden. It could be argued that although Ella’s circumstances would mostly likely be difficult on a practical level, she would take some comfort from the survival of her son as she dealt with the death of her mother. Although her educational progress may be hindered, at least in the short-term, it appears that Ella has the maturity to put her relationships first and understands the centrality of those relationships to her identity and the value they hold for her development. Furthermore, perhaps the clinicians are not being realistic in thinking that Ella would be able to return to her ‘normal life’, when in fact for the last 18 months, it has been anything but the life of a typical teenage girl and that it is unlikely she will be able to resume that if she is dealing with the double bereavement of her mother and son. And even in the worst-case scenario that they were both taken into the care of the State, it still always possible that Ella and Thomas could be reunited in 4 years time when she attains adulthood.

#### 4.4 - Looking beyond Life-Saving Motivations

Although it may be relatively easy to make a case for Ella to donate her kidney to Thomas in order to save his life, would the same considerations justify her donation if the imperative was merely to improve Thomas’s quality of life? Caplan commenting on the newer forms of transplantation such as the hand, face, uterus and voice-box, notes that such procedures are revolutionary because they involve non-life saving organs and are being done ‘to enhance the quality of life or palliate suffering’.<sup>141</sup> Although in Thomas’s case receiving a kidney from his mother Ella may ultimately

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<sup>141</sup> Caplan (n59).

be life-saving, there is an argument that at the present time, there are other alternatives and therefore it is not ethically justifiable.

However, I contend that it is possible to make a strong argument for Ella to donate on the basis of Thomas's quality of life, which will be significantly improved if he is not enduring weekly dialysis sessions.<sup>142</sup> Not only that, but because Ella is his mother and her life is intimately connected to his, thereby her quality of life will be directly and correspondingly improved likewise. Conversely, the strain of life on dialysis for Thomas, would be to all intents and purposes life on dialysis for Ella.<sup>143</sup> But, as Caplan notes, justifying donation on the basis of quality of life '(...) involves a shift in the ethical thinking that has formed the foundation of organ transplantation' that would require a 'rethink of the risk and benefit ratio'.<sup>144</sup> In particular, he draws attention to the potentially significant side-effects of taking immunosuppressants, which ironically include a greater chance of organ failure and a potentially shortened life. He claims that these may not loom-large when facing certain death, but when the transplant is done for quality of life purposes, it 'creates a different risk-benefit ratio: *quality* of life and risk versus *quantity* of life and risk'.<sup>145</sup>

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<sup>142</sup> Marks (n9) 757 cites RS Parekh et al, 'Cardiovascular Mortality in Children and Young adults with End-Stage Kidney Disease' (2002) 141 J Pediatr 191, which claims that compared to transplantation the cardiovascular mortality rate on dialysis is at least doubled.

<sup>143</sup> Broeckx (n86) 56.

<sup>144</sup> Caplan (n59).

<sup>145</sup> *ibid* (Emphasis added).

## **Section 5 - Applying Guideline Three: Evaluation of the Social**

### **Context of Care**

#### **5.1 - Conflict of Interest and Undue Influence?**

One of the key objections to child living organ donation, is the inherent conflict of interest that arises for parents in sibling to sibling donation, where ‘the presumption that parents will act in the best interests of their children is not always reasonable’.<sup>146</sup> In response, Dwyer and Vig claim that far from this being indicative of suspect parental motives, conflict is normal when parents seek to reconcile their desire to help one child whilst not harming another. Indeed in the absence of this conflict ‘they would be bad parents, indifferent to the welfare of one of their children’.<sup>147</sup> This is where care’s scrutinising function would step in to carefully examine the nature of the relationship between the parties and be on guard for any hint of parental pressure or coercion. Although Ella’s situation is in some ways analogous to sibling donation, in other ways the risk of coercion is lessened in that Ella, although still a child herself, as Thomas’s mother acts as a intermediary – and it is her, not Julie who is the driver behind the request to donate.

#### **5.2 - The Role of Religion**

Another broader social theme to be examined under Guideline Three is the role of religion in Ella’s desire to donate and whether that should be assessed as a factor to commend or caution against donation. It is possible that Ella is driven to take extraordinary measures for Thomas as part of a religious ideology that prioritises sanctity of life. When Ella was presented with the option of withdrawal of treatment

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<sup>146</sup> Shartle (n57) 461.

<sup>147</sup> Dwyer (n60) 9-10.

shortly after Thomas birth she refused, and Julie supported her daughter's stance, based on her firm catholic faith. It is not clear whether this was the motivator for Ella's refusal or whether she may be influenced by her mother's views. Even if the latter was the case, it is entirely understandable that at the age of 12 maternal influences would play a large and natural part in Ella's thinking.<sup>148</sup> Faith-based views in and of themselves should not be a cause for concern over donation. However, even if their catholic faith underlay Ella and Julie's refusal to consent to withdrawal of treatment, it does not necessarily follow that such faith would require positive, and heroic steps, such as bodily sacrifice in order to save his life.

### 5.3 - Protectionism and the Welfare of the Child

Finally, the cautionary approach some of clinicians in Ella's case, to use dialysis as a holding mechanism until she reached the age of 16 and could consent for herself, reveals a prevailing social attitude of protectionism towards children, the justification of which should be questioned. The first point to make is that this stance is based on a misunderstanding of the law, as Lord Donaldson in *Re W*<sup>149</sup> confirmed that the provisions of the FLRA 1969, which allow 16 and 17-year-olds to consent as though they were adults,<sup>150</sup> does *not* apply in cases of non-therapeutic procedures. This stands in contrast to the more recent construction of competence, even for children younger than 16, as seen in *ABC*.<sup>151</sup> One interpretation of the judgment in *ABC* is that the court was making a genuine statement that the competent child should be treated in the same 'present-facing' manner as adults. This would allow them to make decisions, as can adults, which are ultimately not in their best interests but respect the

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<sup>148</sup>Jonathan Herring, 'An Injection of Sense' [8 November 2013] NLJ 9, 10.

<sup>149</sup> *Re W* (n26).

<sup>150</sup> S8.

<sup>151</sup> *ABC* (n28).

reality of their present situation or viewpoint - in other words the right to make their own mistakes.<sup>152</sup> This is in contrast to the future-orientated, protectionist stance, that is traditionally taken in children's decision-making and appears to have been the rationale underlying the clinicians position in Ella's case.

Secondly on a more practical level, this would mean that the presumption would not take effect until Ella was 18, resulting in 4 years of dialysis for Thomas. Brierley and Larcher have identified the argument that time on dialysis can be effectively used for the potential donor child to mature to adulthood, whilst the recipient child remains on the cadaveric waiting list.<sup>153</sup> However, the latter option is not available to Thomas, and if he were to survive for that long on dialysis there would still remain the attendant burdens to the quality of life of both Ella and Thomas.

## **Concluding Thoughts**

This case study has tackled an important issue both in terms of social policy and the scope for individual children to participate in health interventions that do not benefit them directly. It has demonstrated that paediatric living organ donation presents us with some unique legal and ethical challenges when the donor is a child in mid-childhood. Ella's case allowed for a demonstration of if and how a child could be *Gillick* competent to make the decision to become donor, by carefully assessing the individual child in her particular circumstances. Her unique circumstances of maternal experience, relational vulnerability and embodied understanding, made it easier to justify her competence – a task which may be much more difficult for most children

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<sup>152</sup> Moreton (n64) 307.

<sup>153</sup> Joe Brierley and Vic Larcher, 'Organ Donation from Children: Time for Legal, Ethical and Cultural Change' (2011) 100 *Acta Paediatrica* 1175,1178.



in mid-childhood. Nonetheless by applying the Ethics of Care framework, particularly Guideline Two, important issues surrounding the broad construction of welfare to encompass social, relational and psychological interests highlighted the fact that child donation can be justified in the child's best interests. The consideration of the role of obligation within families, gave a strong basis for Ella's claim to donate as Thomas's mother, but would which would still be effective in other circumstances, such as sibling-sibling donation. Finally, the Ethics of Care model allowed crucial questions around how the forces of parental interests and the influence of religious or other values to be placed in a realistic context within intimate relationships. As Crouch and Elliott note, 'when it comes to moral decisions about the family, the tools of moral philosophy and the law have not always served us well, particularly when the question involves exposing one family member to risks for the sake of another'.<sup>154</sup> I contend that the Ethics of Care model is a better servant.

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<sup>154</sup> Crouch (n106) 275.

**CHAPTER 6**

**TREATMENT PROTOCOLS FOR TRANSGENDER**

**CHILDREN IN MID-CHILDHOOD**

**CASE STUDY THREE**

*‘I think I’m a good face for transgender. After years of heartache, I want people to understand that we are not weirdos or freaks or any of the other horrible terms thrown at us. As far as I’m concerned, I’m just a normal girl with a bit of an interesting history’.*

– Jackie Green.<sup>1</sup>

**Introduction**

In May 2016, the Obama administration in the USA introduced new federal rules that it was “best practice” for all school districts to make provision for transgender children to be able to use the locker room and toilets that matched the gender with which they identified.<sup>2</sup> Underpinned by anti-bullying motivations, President Obama drew on the societal imperative to protect vulnerable children to claim that these new

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<sup>1</sup> Nikki Murfitt and Toni Jones, ‘Pausing Puberty aged 12 Saved my Life: Transgender Beauty Queen Praises her Amazing Family Ahead of BBC Documentary on her Mission to become Miss England’ Mail Online (3 November 2012).

<sup>2</sup> Gregory Korte, ‘Transgender Bathroom Rule a Matter of Dignity, Obama says’ USA Today (16 May 2016) <[www.usatoday.com/story/news/politics/2016/05/16/transgender-bathroom-rule-matter-dignity-obama-says/84460430/](http://www.usatoday.com/story/news/politics/2016/05/16/transgender-bathroom-rule-matter-dignity-obama-says/84460430/)> <Accessed 10 August 2016> Additionally these rules came with teeth - taking their rationale from sex discrimination law Title XI, which meant that breach carried the threat of federal enforcement, in particular, loss of educational funding.

rules would make sure that ‘everyone is treated fairly, and our kids are all loved and protected, and that their dignity is affirmed’.<sup>3</sup> However, what might have appeared to be an innocuous measure motivated by compassion, was actually ‘an arrow aimed straight at the heart of the conservative south’,<sup>4</sup> as a month earlier the state of South Carolina had passed laws declaring that transgender people had to use the bathrooms that accorded with the sex recorded on their birth certificate.<sup>5</sup> A fierce debate ensued, exemplified by the “Target bathroom controversy”<sup>6</sup> and the formation of a thirteen state coalition<sup>7</sup> with a mandate to fight against such ‘federal over-reach’.<sup>8</sup>

Although the substantive matter may seem trivial, it nonetheless aptly illustrates some of the legal and ethical tensions identified in Chapter 2 and discussed in the Systematic Review in Chapter 3, which appear amplified in the case of transgender children. On one hand, there is growing recognition of, and sympathy for, the needs of transgender children in terms of their access to healthcare and treatment, and their right to fairness and equality within school and the public space. On the other, there is apparent fear within the public mind of the “strangeness” of trans-identities and suspicion around potential treatments and interventions to address Gender Dysphoria.

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<sup>3</sup> *ibid*

<sup>4</sup> Mary Wakefield, ‘Why is Obama so obsessed with transgender toilet rights?’ *Spectator* (21 May 2016) <[www.spectator.co.uk/2016/05/save-the-ladies-toilet](http://www.spectator.co.uk/2016/05/save-the-ladies-toilet)> <Accessed 2 August 2016>.

<sup>5</sup> The law was passed 23 March 2016. See Valerie Bauerlein et al, ‘Eleven States sue Obama Administration over Transgender Bathroom Policy’ *The Wall Street Journal* (25 May 2016) [www.wsj.com/articles/eleven-states-sue-obama-administration-over-transgender-bathroom-policy-1464207455](http://www.wsj.com/articles/eleven-states-sue-obama-administration-over-transgender-bathroom-policy-1464207455) <Accessed 2 August 2016>

<sup>6</sup> Target issued a statement that said that transgender customers were welcome to use the bathroom that matches the gender with which they identify. There was huge backlash to this in certain sectors of the public with customers boycotting stores and protesting. See Robert Mclean, ‘Target takes stand on Transgender Bathroom Controversy’ *CNN* (20 April 2016) <[money.cnn.com/2016/04/20/news/companies/target-transgender-bathroom-lgbt/](http://money.cnn.com/2016/04/20/news/companies/target-transgender-bathroom-lgbt/)> <accessed 28 July 2016>

<sup>7</sup> Bauerlein (n5) The 11 states originally suing were Texas, Alabama, Wisconsin, West Virginia, Tennessee, Arizona, Oklahoma, Louisiana, Utah, Georgia and Maine. They were later joined by Kentucky and Mississippi, see Wapt News, ‘Mississippi Joins Suit against Obama Transgender Bathroom Plan’ (7 July 2016) <[www.wapt.com/news/central-mississippi/jackson/mississippi-joins-suit-against-obama-transgender-bathroom-plan/40399090](http://www.wapt.com/news/central-mississippi/jackson/mississippi-joins-suit-against-obama-transgender-bathroom-plan/40399090)>

<sup>8</sup> Wakefield (n4).

This is compounded within the social and political sphere with perceived risks to public safety posed by meeting the needs of transgender children,<sup>9</sup> and questions of justice around the clash of minority rights<sup>10</sup> and allocation of resources.<sup>11</sup> Thus, the issues surrounding transgender children present a fitting topic for a case study to demonstrate how to balance the very private considerations around gender identity, physical appearance, and the impact of transgender experience upon family relationships, with the larger questions of societal expectations around gender roles, and justice and fairness regarding public policy and allocation of healthcare resources.

Of course such debates are not confined to the USA, and as Mary Wakefield notes in her commentary on the Obama policy in the *Spectator*, '[w]ho's right? who's wrong? It's tempting to say who cares? Except that we're all going to have to care soon, because inevitably American's toilet war will cross the Atlantic'.<sup>12</sup> Indeed, there has been much discussion of late in the UK context about the nature, diagnosis, and treatment of transgender children and adolescents, and it is upon these issues that I shall focus. For example, two recent television documentaries detailing the stories of transgender children and adolescents, have tackled important questions around the origins of transgenderism in children, and whether it should be viewed as a "phase" which most children outgrow, a result of environmental and parental influence, a mental disorder, or merely an alternative expression of gender identity with biological

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<sup>9</sup> Meg Wagner, 'Bible-Toting Mom marches through Target, Screams in Protest over Transgender Bathroom Policy: "Are you gonna let the Devil Rape your Children"' *Daily News* (17 May 2016).

<sup>10</sup> Wakefield (n4). Wakefield argues that the trans bathroom controversy involves a collision of minority rights: equal access for transgender people but then the right for women and girls to be safe from assault from those who would use the policy to pose as transgender merely to 'gain access and grope girls'.

<sup>11</sup> Riham Feshir, 'Target Transgender Bathroom Policy Sparks Opposition Campaign' MPR News (16 May 2016).

<sup>12</sup> Wakefield (n4).

roots.<sup>13</sup> Additionally, these documentaries considered the debate around treatment for those who are distressed by their transgender feelings, and whether it is a child's best interest for parents to consent to these treatments or indeed if the child is competent to consent for themselves. This discussion hones in on the question of whether therapy should be offered to help the child's mind match their bodily reality, or whether medical interventions such as hormone blockers, cross-sex hormones and ultimately gender reassignment surgery should be offered to help to correct the "wrong" body so that it aligns with the child's sense of gender identity.

This case study will be centred on the story of Jackie Green, a trans girl who was diagnosed with Gender Dysphoria as a young child, received hormone treatment in early adolescence in the USA, and went on to become the world's youngest person to undergo gender reassignment surgery at the age of 16.<sup>14</sup> The sources for Jackie's story will consist of entries from the website *Mermaids*, along with media reports, YouTube videos and notes from her television appearances.<sup>15</sup> As in the earlier case study chapters, each of the three guidelines of the Ethics of Care framework will be considered in turn but in this chapter particular focus will be given to Guideline Three. First, within Guideline One I will consider the process of identification of transgender children. I will also discuss whether the typical diagnostic procedures using social constructions of 'normal' gendered behavior are merely forcing everyone to fit into the traditional gender binary. This will be contrasted with the Ethics of Care's approach of viewing this individual child within her particular context to ask

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<sup>13</sup> Louis Theroux, *Transgender Kids* (BBC2, 5 April 2015); Michael Hogan, "Louis Theroux: Transgender Kids, Review: "Excellent Storytelling" *Telegraph* (5 April 2015); Victoria Derbyshire, 'The Story of two transgender children' (7 April 2015) BBC News < [www.bbc.co.uk/news/magazine-32037397](http://www.bbc.co.uk/news/magazine-32037397)>

<sup>14</sup> Julian Gaughan, 'Teenager who became Youngest Person to have Sex Change clinches Semi-Final Spot in Miss England Contest' Mail Online (20 May 2013).

<sup>15</sup> <[www.mermaidsuk.org.uk](http://www.mermaidsuk.org.uk)>; BBC3, 'Transsexual Teen, Beauty Queen' (20 November 2012).

what is “natural” for that child - and if this indicated the presence of 3<sup>rd</sup> or 4<sup>th</sup> sex, to consider if this could and should be accommodated by the law. Additionally I will ask whether procedures aimed at addressing Gender Dysphoria are medical treatment at all, and if so can a child ever be *Gillick* competent to consent to them. Understanding the child’s embodied experience and attempting to tie this to the modern diagnostic requirement of ‘dysphoria’ will also be key to my arguments that the Ethics of Care approach will better able us to discern the most ethically appropriate cause of action for the child experiencing a transgender identity. Furthermore, I shall also draw on the notions of vulnerability and trust that were discussed in Chapter 1,<sup>16</sup> to examine the benefits and pitfalls of offering a medicalised solution to gender dysphoria, with the attendant potential to irreversibly change the child’s body.

Within Guideline Two, I contend that the impact of the child’s interconnected experience with family members and peers is crucial to a “caring” approach to transgender children and can be the key to decision-making around treatment and whether the outcome is more likely to be successful. Here the Ethics of Care framework will better enable us to uncover the child’s possible discomfort in how they view themselves and how this affects their relationships with others. Under Guideline Three I will contend that the Ethics of Care framework can help us to balance the apparently competing claims of individual and relational care, and societal justice. I will consider whether the social construction of gender has played a large part on the negative effects of labeling and stigma associated with being transgender, which might create or add to the sense of dysphoria these children feel. Further, I will consider the impact of education and social policy on the apparent

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<sup>16</sup> See Chapter 2.

clash between meeting the needs of transgender children and those of other minority groups such as women. Finally Guideline Three will assess the arguments around the allocation of healthcare resources to offer expensive treatments that outside of a psychiatric diagnosis may appear to be cosmetic but may also alleviate significant distress in the transgender child, averting potential self harm and even suicide.

## **Section 1 - Transgender Children: The Law, Medicine, and**

### **Professional Guidance.**

#### **1.1 -What is Transgenderism?**

Transgender (or gender variant) is a broad term to describe people whose gender identity does not conform to their natal assigned sex.<sup>17</sup> In some cultures gender variance is recognized and even celebrated. For example, in Samoa alongside the traditional male and female, a third gender - Fa'afafine, or effeminate male is socially accepted.<sup>18</sup> Native American tribes go further still and not only recognize "Two-Spirit" people but view them as 'doubly blessed, having both the spirit of a man and the spirit of a woman' and revere them for being more spiritually gifted.<sup>19</sup> However in the western world transgenderism if recognized at all has often been misunderstood and feared. Transgender people may express their gender variance in a range of ways including identifying as genderqueer,<sup>20</sup> by occasional cross-dressing, full social transition, and seeking medical intervention. However it is common for transgender people to suffer 'gender dysphoria' which is defined as the distress or discomfort

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<sup>17</sup> Bernard Reed et al, 'Gender Variance in the UK: Prevalence, Incidence, Growth and Geographic Distribution' GIRES (June 2009) 7.

<sup>18</sup> P Vasey and N Barlett, 'What can the Samoan "Fa'afafine" Teach us about the Western Concept of Gender Identity Disorder in Childhood?' (2007) 50(4) Perspectives in Biology and Medicine 481.

<sup>19</sup> Walter L Williams, 'The Two-Spirit People of Indigenous North Americans' *The Guardian* (11 October 2010).

<sup>20</sup> Genderqueer is a term for those who reject the gender binary and express their gender non-normatively.

arising from not only the dissonance between body and mind but also the stigmatization that comes from non-conformity to traditional gender expressions and roles.<sup>21</sup> For those whose dysphoria is particularly severe, they may choose to “transition” by receiving medical intervention by way of hormone treatments and/or surgery to help their body to conform to their expressed gender – this subset of transgender people are known as transsexual.<sup>22</sup>

The etiology of transgenderism is unknown to date,<sup>23</sup> although Polly Carmichael, lead clinician at the Tavistock clinic notes, ‘its likely to be a combination of environmental, genetic and biological factors’.<sup>24</sup> In terms of genetic links, studies on twins indicate that transgenderism is 62% heritable.<sup>25</sup> Alternatively, exposure or lack of exposure to hormones in the womb may be a cause, as studies have shown that in male-to-female transgendered people gender dysphoria is associated with variations in an individual's genes that diminish sensitivity to androgens.<sup>26</sup> A further possibility is differences in brain structure and function, with Zhou et al claiming that in one area of the brain, male-to-female transsexuals have a typically female structure, and female-to-male transsexuals have a typically male structure.<sup>27</sup> The prevalence of transgender people in the UK is hard to quantify as many do not present for medical treatment and others may self-treat with hormones purchased on the internet.<sup>28</sup> There have been no major governmental surveys that have asked a question allowing trans

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<sup>21</sup> Reed (n17) 7.

<sup>22</sup> *ibid*

<sup>23</sup> Andrew Sharpe, *Transgender Jurisprudence: Dysphoric Bodies of Law* (Cavendish Publishing Limited 2002) 28.

<sup>24</sup> Murfitt (n1).

<sup>25</sup> Milton Diamond, *Transsexuality among Twins: Identity Concordance, Transition, Rearing and Orientation* (2013) 14(1) *International Journal of Transgenderism* 24.

<sup>26</sup> PT Cohen-Kettenis and F Pfafflin, *Transgenderism and Intersexuality in Childhood and Adolescence: Making Choices* (Sage 2003).

<sup>27</sup> Jiag-Ning Zhou et al, ‘A Sex Difference in the Human Brain and its Relation to Transsexuality’ (1995) 378 (6552) *Nature* 68.

<sup>28</sup> Reed (n17) 8.



people to identify themselves.<sup>29</sup> However the Gender Identity Research and Education Society (GIRES) estimates that about 1 % of the UK population are gender variant.<sup>30</sup>

Whatever the cause, within the last two decades there has been a growing incidence of those presenting with transgender feelings.<sup>31</sup> This is evidenced by figures published in 2015 by the UK's only treatment centre for transgender children - London's Tavistock and Portman Clinic, that the number of even very young children referred to them (those aged under 10) for treatment for "transgender feelings" has more than quadrupled in the last 5 years.<sup>32</sup> In 2015, 1,400 children were referred to the Tavistock clinic, double the number referred in 2014. Of these approximately, 900 were aged between 12 and 18.<sup>33</sup> Carmichael notes of the increased referral rate that 'it is likely that this is linked to greater awareness and tolerance of gender variance and young people are using social media to explore their gender'.<sup>34</sup>

Treatment can run the gamut from therapy; to social transitioning; to the administration of hormone blockers to halt puberty; to the application of cross-sex hormones; and ultimately gender reassignment surgery. Yet none of these approaches is uncontroversial. Whilst therapy may be useful to help people experiencing Gender Dysphoria to explore their feelings, consider the image they would like to portray to

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<sup>29</sup> Elizabeth Day, 'Transgender Kids: 'Everyone was calling me Sebastian, but I knew I was a Girl' *The Guardian* (5 April 2015).

<sup>30</sup> GIRES <[www.gires.org.uk](http://www.gires.org.uk)>

<sup>31</sup> Dr James Barrett – lead clinician at London Mental Health Trust's Gender Identity clinic claims that in the year to April 2009 the clinic had 1500 referrals and that numbers keep rising and we don't know why. The gender ratios also changing; whereas it used to be 1 female to every 9 males, now the ratio is about 1:3.

<sup>32</sup> Laura Donnelly, 'Rise in Child Transgender Referrals' *The Telegraph* (7 April 2015). This included 47 children aged 5 or under and 2 children aged 3.

<sup>33</sup> Tim Adams, 'Transgender Children: The Parents and Doctors on the Frontline' *The Guardian* (13 November 2016).

<sup>34</sup> Joseph Patrick McCormick, 'Interview: Jackie Green, the First Trans Miss England?' *Pink News* (27 January 2012) <[www.pinknews.co.uk/2012/01/27/interview-jackie-green-the-first-trans-miss-england/](http://www.pinknews.co.uk/2012/01/27/interview-jackie-green-the-first-trans-miss-england/)>

the world, or explore their options, some conservative think-tanks and religious groups advocate reparative therapy as ‘a perfectly proper procedure of medicine’.<sup>35</sup> The Transgender Human Rights Institute argue that to do so harks back to the “dark days” of harmful homosexual conversion therapy.<sup>36</sup>

In contrast, the preferred modern solution would be the option of medical intervention. Yet, there are those who express grave concerns about the ethical grounds for intervening to “mutilate” a healthy and functioning physical body, with consequent and potentially irreversible effects to a person’s physical appearance, sexual functioning and fertility.<sup>37</sup> There is a third concern around categorizing transgenderism as a disorder, or pathologising “dysphoria” at all. This is the criticism that by so doing we are seeking to medicalise what could be understood as a naturally occurring variation in gender expression, which is pathologised merely because it sits outside of the traditional masculine/feminine binary.<sup>38</sup>

### 1.2 - Medicalising Transgenderism - Disorder or Dysphoria?

Many trans rights support groups such as GIRES<sup>39</sup> contend that transgender feelings should not be construed as a mental disorder as this merely acts to pathologize what is normal albeit unusual gender expression.<sup>40</sup> However, psychoanalytical accounts still

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<sup>35</sup> Carlos D Flores, ‘The Absurdity of Transgenderism: A Stern but Necessary Critique’ (6 Feb 2015) *Public Discourse*, The Witherspoon Institute <[www.thepublicdiscourse.com/2015/02/14305/](http://www.thepublicdiscourse.com/2015/02/14305/)>

<sup>36</sup> Transgender Human Rights Institute, ‘Enact Leelah’s Law to Ban Transgender Conversion Therapy’ Petition on Change.org

<sup>37</sup> Flores (n35)

<sup>38</sup> Christin Scarlett Milloy, ‘Don’t let the Doctor do this to your Newborn’ *Outward* (26 June 2014) <[www.slate.com/blogs/outward/2014/06/26/infant-gender-assignment-unnecessary-and-potentially-harmful.html](http://www.slate.com/blogs/outward/2014/06/26/infant-gender-assignment-unnecessary-and-potentially-harmful.html)> <accessed 6 August 2016>.

<sup>39</sup> <[www.gires.org.uk](http://www.gires.org.uk)>

<sup>40</sup> L Newman, ‘Sex, Gender and Culture: Issues in the Definition, Assessment and Treatment of Gender Identity Disorder’ (1 July 2002) 7 (3) *Clinical Child Psychology and Psychiatry* 352.

hold sway,<sup>41</sup> and the personal and social reality for many children is that they will feel distress at their gender variance and wish to access healthcare support and treatment. The gateway to this support is often through a referral from the Child and Adolescent Mental Health Service (CAMHS), and transgenderism is still treated as a psychiatric diagnosis.

The current incarnation of what was in the past referred to by the diagnostic label of Gender Identity Disorder is 'Gender Dysphoria'.<sup>42</sup> In the DSM-5, this new label is intended to represent a shift in thinking around gender identity, which moves the emphasis solely from issues of identity to those of *distress*. This is an attempt to signal that 'gender nonconformity is not in itself a mental disorder'.<sup>43</sup> The distress may arise as a result of the dissonance felt between body and mind, particularly around the development of secondary sexual characteristics, or may be a product of the stigma felt as a result of non-conformity to socially expected gender roles and expression.<sup>44</sup>

For a diagnosis of gender dysphoria in children, the DSM-5 requires a 'marked incongruence between one's experienced/expressed gender and assigned gender of at least six months duration'.<sup>45</sup> This is to be demonstrated by 'a strong desire to be of the other gender or an insistence that one is the other gender (or some alternative gender

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<sup>41</sup> Sharpe (n23) 28-29.

<sup>42</sup> NHS Choices, 'Gender Dysphoria' <[www.nhs.uk](http://www.nhs.uk)>. This diagnostic label replaces the previously used 'Gender Identity Disorder', as of the release of the DSM-5 on 22 May 2013.

<sup>43</sup> American Psychiatric Association, 'Gender Dysphoria' (American Psychiatric Publishing 2013).

<sup>44</sup> Wynne Parry, 'Gender Dysphoria: DSM-5 Reflects Shift in perspective on Gender Identity' Huffington Post (4 June 2013) <[www.huffingtonpost.com/2013/06/04/gender-dysphoria-DSM-5\\_n\\_3385287.html](http://www.huffingtonpost.com/2013/06/04/gender-dysphoria-DSM-5_n_3385287.html)> (Last Accessed 28 May 2016).

<sup>45</sup> DSM-5, *Gender Dysphoria: Gender Dysphoria in Children*, 302.6 (F64.2).

from one's assigned gender),<sup>46</sup> plus 5 out of 7 additional criteria.<sup>47</sup> In addition, this must be associated with 'clinically significant distress or impairment in social, school or other important areas of functioning'.<sup>48</sup> For adolescents, the 6 months stipulation remains but this only needs to be evidenced by two out of five criteria.<sup>49</sup> The standard approach to treatment, following the Dutch protocol is to administer puberty blocking hormones from the age of 12, cross-sex hormones to affect the development of secondary sexual characteristics of the chosen gender from the age of 16, and then if so desired the option for gender reassignment surgery from the age of 18.

## **Section 2 - Relevance to Mid-Childhood**

### **2.1 - The Impact of Puberty**

Although referrals to Gender Identity Services can occur from as young as the age of 3, most children are referred in the period of mid-childhood.<sup>50</sup> This period is relevant as contains the onset of puberty, which is somewhere around the age of 10 -12 for girls and age 12-14 for boys. The commencement of puberty often acts as the trigger for the first stage of medical intervention – the administration of hormone blockers to

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<sup>46</sup> DSM-5, *Gender Dysphoria: Gender Dysphoria in Children*, 302.6 (F64.2), Criterion A1.

<sup>47</sup> A2 – In boys (assigned gender) a strong preference for cross-dressing or simulating female attire; or in girls (assigned gender), a strong preference for wearing only typical masculine clothing and a strong resistance to the wearing of typical female clothing; A3- A strong preference for cross-gender roles in make-believe play or fantasy-play; A4- A strong preference for the toys, games or activities stereotypically used or engaged in by the other gender; A5- A strong preference for playmates of the other gender; A6- In boys (assigned gender), a strong rejection of typically masculine toys, games and activities and a strong avoidance of rough-and-tumble play; or in girls (assigned gender) a strong rejection of typically feminine toys, games or activities; A7 – A strong dislike of one's sexual anatomy; A8 – A strong desire for the primary and/or secondary sex characteristics that match one's experienced gender.

<sup>48</sup> DSM-5, *Gender Dysphoria: Gender Dysphoria in Children*, 302.6 (F64.2), Criterion B.

<sup>49</sup> Preoccupation with getting rid of primary and secondary sex characteristics (requests hormones, surgery, or other procedures to physically alter sexual characteristics to simulate the other sex)' Belief that he/she was born the wrong sex; A marked incongruence between one's experienced/expressed gender and primary and/or secondary sex characteristics (or in adolescents, the anticipated secondary sex characteristics); A strong desire for the primary or secondary sex characteristics of the other gender; A strong desire to be treated as the other gender; A strong conviction that one has the typical feelings and reactions of the other gender.

<sup>50</sup> Tavistock and Portman Clinic – average age for referral was 14 in 2015-16.

halt the development of secondary sexual characteristics. The desire for intervention often stems from the growing awareness of the body during mid-childhood, and revulsion at unwanted physical changes.<sup>51</sup>

Furthermore although the rate of desistence is high in young children,<sup>52</sup> after puberty the rate of persistence is equally high.<sup>53</sup> Polly Carmichael notes that ‘80% of those referred to us pre-puberty will not go ahead with sex reassignment surgery and will find another solution such as living as a lesbian or gay man. Post-puberty 80% of referrals will go ahead with it.’<sup>54</sup>

## 2.2 - Legal Issues

The key legal issues in relation to transgenderism in mid-childhood concern the definition of “treatment” and whether a child could be *Gillick* competent to provide consent. Should the child not reach the competence threshold, the best interests test will be used by clinicians or the courts to determine which is the course of action that will best meet the child’s interests. Finally, the treatment of transgender children within the public sphere may raise issues discrimination. For those children over the age of 16, as discussed in Chapter 2, s8 of the FLRA 1969 would in general permit the child to consent to treatment as though they were an adult. However, as discussed in Section 3.1 below, there is controversy over whether hormone therapy can properly be considered medical “treatment” at all and therefore whether it would fall within the provisions of the Act. Of greater relevance to children in mid-childhood is whether a

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<sup>51</sup> Jacqueline K Hewitt et al, ‘Hormone Treatment of Gender Identity Disorder in a Cohort of Children and Adolescents’ (2012) 196(9) *Med J Aust* 578.

<sup>52</sup> Only 16% of pre-pubertal children diagnosed with Gender Dysphoria, will persist into adolescence and adulthood. See Hewitt (n51).

<sup>53</sup> If a child persists with transgender feelings by the onset of puberty, 80% of those children will persist throughout adolescence and adulthood. Nikki Murfitt and Toni Jones, ‘Pausing Puberty aged 12 Saved my Life: Transgender Beauty Queen praises her amazing family ahead of BBC Documentary to become Miss England’ *Mail Online* (3 November 2012).

<sup>54</sup> Tavistock Clinic Sideways News, ‘What’s in a Gender?’ (11 February 2010).

finding of *Gillick* competence would enable a child under 16 to consent to receiving treatment for Gender Dysphoria, or on what basis this treatment could be construed to be in the child's best interests. Finally, matters of equality are dealt with by legislation, including the possibility of the affirmation of a different gender than the one assigned at birth by way of a gender recognition certificate under the Gender Recognition Act 2004. However, at present its provisions only apply to those aged over 18.<sup>55</sup> There have not been any cases in courts of England and Wales on the matter of child or parental consent to treatment for Gender Dysphoria. However, there have been two cases that address transgender identity. The first is the case of *PD v SD, JD and X County Council*,<sup>56</sup> which concerns the Article 8 ECHR rights of a child with respect to his medical information. The second is the very recent case of *Re J*,<sup>57</sup> which involved a Child Arrangements Order for a 7 year-old boy who had been 'living by stealth' as a girl since the age of 5. Both cases are discussed more fully in the analysis sections below.

### 2.3 - Treatment in the UK: The Tavistock and Portman Clinic Protocol

The Tavistock and Portman Clinic based in London, is the UK's only specialist treatment centre for transgender children. Prior to 2011, NHS Guidance stated that no treatment to address transgenderism could commence before the age of 16. However, there were calls from trans support groups such as GIRES to implement the World Professional Association for Transgender Health (WPATH) Standards of Care,<sup>58</sup> which advocate the Dutch protocol of the early administration of hormone blockers to

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<sup>55</sup> S1.

<sup>56</sup> [2015] EWHC 4103 (fam); [2016] Fam Law 561

<sup>57</sup> (*A Minor*) [2016] EWHC 2430 (Fam).

<sup>58</sup> WPATH : Standards of Care (Version 7).

delay puberty.<sup>59</sup> Likewise the Endocrine Society had issued guidelines for the treatment of adolescents with puberty blocking hormones.<sup>60</sup>

Between April 2011 and April 2014, doctors at the clinic, lead by Polly Carmichael, undertook a 3-year trial involving 32 children aged 12-14 year olds who were diagnosed with Gender Dysphoria.<sup>61</sup> The trial involved administering gonado-trophin releasing hormone (GnRH) analogues, at Tanner Stage 2-3 in order to pause puberty.<sup>62</sup> The rationale behind the administration of puberty blockers is tri-fold; first to reduce the trauma for the child of undergoing the puberty of their assigned sex, second to “buy time” to allow the child to explore their gender identity; and third to better prepare the body should they later wish to transition, by preventing secondary sex changes which are difficult to reverse.<sup>63</sup> Laura Donnelly describes the treatment:

The drugs, known as hypothalamic blockers, stunt the development of sexual organs so less surgery is required if a child chooses to change sex after reaching adolescence. Monthly injections into the stomach suppress the production of testosterone and oestrogen. In girls that halts the menstrual cycle and the development of breasts. In boys, they stop facial hair growing and voice changes.<sup>64</sup>

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<sup>59</sup> Annelou LC de Vries and Peggy Cohen-Kettenis, ‘Clinical Management of Gender Dysphoria in Children and Adolescents: The Dutch Approach’ (2012) 59 *Journal of Homosexuality* 301.

<sup>60</sup> Hembree WC et al, *Endocrine Treatment of Transsexual Persons* (2013) An Endocrine Society Clinical Practice Guideline.

<sup>62</sup> The Tanner Stages are scales that measure physical development in children and adolescents. Tanner Stages 2-3 marks the first signs of puberty, with the development of breast buds and enlargement of breast and areola in girls, and the beginning of testes and penile enlargement in boys. Children typically reach stages 2-3 between the ages of 10-13 years old.

<sup>63</sup> Hewitt (n51) 578.

<sup>64</sup> Laura Donnelly, ‘Rise in Child Transgender Referrals’ *The Telegraph* (7 April 2015).

In the Tavistock trial, only eight of the 32 children later went on to start the sex change process by receiving cross-sex hormones.<sup>65</sup> The trial was hailed a success and up to 142 children aged 11-15 have since been referred, with plans to continue the programme indefinitely.<sup>66</sup> Indeed, not only were there benefits to beginning the treatment at age 12, but the clinic claimed children as young as nine or ten could be offered such drugs in future.<sup>67</sup>

The legal and ethical issues that this treatment protocol raises will now be discussed by analysing the case of Jackie Green:

### **Section 3 - The Case of Jackie Green**

Assigned at birth as male, Jackie Green started out life as Jack – the eldest of 4 boys.<sup>68</sup> However, most of her childhood was spent trying to convince her parents that she was born in the wrong body.<sup>69</sup> At nursery Jack never played with the boys and always chose soft toys and girls' dressing up.<sup>70</sup> Whilst this kind of exploration in play is common amongst young children, by the age of 4, Jack declared to her mother Susie that 'God has made a mistake, I should be a girl'.<sup>71</sup> Her mother sought a referral to London's Tavistock and Portman clinic where Jack was diagnosed with Gender

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<sup>65</sup> Report of Tavistock Clinic (April 2014)

<sup>66</sup> Sanchez Manning, 'NHS to give Sex Change Drugs to Nine Year-Olds: Clinic accused of playing God with Treatment that Stops Puberty' *Daily Mail* (17 May 2014).

<sup>67</sup> *ibid*

<sup>68</sup> Lucy Thornton, 'Sex-Change Beauty Queen: Transgender Teenager wins place in the Miss England Semi-Final' *Mirror* (8 May 2012).

<sup>69</sup> Murfitt (n1).

<sup>70</sup> Angeline Albert, 'Transgender Children: "I first noticed Jackie was different when she was 18 months old"' [daynurseries.co.uk](http://daynurseries.co.uk) (29 October 2015) <[www.daynurseries.co.uk/news/article.cfm/id/1571947/transgender-children-How-nurseries-can-support-those-with-gender-identity-issues](http://www.daynurseries.co.uk/news/article.cfm/id/1571947/transgender-children-How-nurseries-can-support-those-with-gender-identity-issues)>

<sup>71</sup> Murfitt (n1).



Dysphoria at the age of 5.<sup>72</sup> At 8 years old, Jack socially transitioned by sending an email to his primary school declaring he was a girl trapped in a boy's body and began wearing girls' clothes and adopting the name Jackie and female pronouns.<sup>73</sup> However, Jackie was bullied at school and at her lowest point she threatened to cut off her genitals with a knife.<sup>74</sup> She overdosed at the age of 11 and attempted suicide six more times before the age of 15.<sup>75</sup> Eventually her mother Susie contacted Dr Norman Spack, Paediatric Endocrinologist at Boston Children Hospital, who had established the USA's first paediatric gender management clinic in 2007. At this time, no transgender medical treatment was offered in the UK to anyone under the age of 16. Dr Spack describes how Jackie was when he first met her:

Jackie had been abused in the Midlands, in England. She's 12 years old there, she was living as a girl, but she was being beaten up. It was a horror show, they had to home school her. And the reason the British were coming was because they would not treat anybody with anything under age 16, which means they were consigning them to an adult body no matter what happened, even if they tested them well. Jackie, on top of it, was, by virtue of skeletal markings, destined to be six feet five. And yet, she had just begun a male puberty.<sup>76</sup>

Jackie's case was somewhat unusual in that as well as being prescribed hormone blockers, at the age of 13 she was also given cross-sex hormones, which children do not typically commence until the age of 16. Spack explains that the reason for this

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<sup>72</sup> *ibid*

<sup>73</sup> *ibid*

<sup>74</sup> Gaughan (n14).

<sup>75</sup> Murfitt (n1).

<sup>76</sup> Norman Spack 'How I help Transgender Teens become who they want to be' TED Talk (November 2013).

was that oestrogen is much more potent in closing epiphyses - the growth plates, than testosterone is, which was vital if Jackie was not going to grow to her full height of 6 foot 5 inches.<sup>77</sup> Because of the early hormone treatment, Jackie never grew masculine features, her voice never deepened and she eventually grew to 5 foot 11 inches.<sup>78</sup> Jackie went to Boston every six months for hormone therapy until on her 16th birthday she became the young person to undergo a full gender reassignment surgery by travelling to Thailand (which at that time permitted such surgeries on under 18's).<sup>79</sup> Jackie was offered contracts as a model and at the age of 19 Jackie gained publicity as she became the first transgender competitor in the Miss England competition, where she reached the semi-final.<sup>80</sup>

## **Applying the Ethics of Care Framework to the Case of Jackie Green**

### **Section 4 - Applying Guideline One: Attentiveness to the**

#### **Interconnected Individual Child in her Particular Circumstances.**

##### **4.1 – Is it treatment? Consenting to Hormone Therapy or Gender Reassignment Surgery**

Applying an Ethics of Care framework to the issue of treatment for Gender Dysphoria would confirm the Tavistock protocol as being an appropriate response. Under Guideline One earlier intervention than has been permitted in the past is an expression of becoming engrossed in the child's present reality, rather than delaying treatments

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<sup>77</sup> *ibid*

<sup>78</sup> Murfitt (n1).

<sup>79</sup> Murfitt (n1). Thailand have since changed their laws to conform with the International recommendation that surgery should not be performed on children under the age of 18.

<sup>80</sup> Lucy Thornton, 'Sex-Change Beauty Queen: Transgender Teenager wins place in the Miss England Semi-Final' *Mirror* (8 May 2012).

until adulthood. In Chapter 2, I discussed Feinberg's argument on the pursuit of the 'right to an open future'<sup>81</sup> as a means of delaying decision-making that might have long- term impact, until the attainment of adult autonomy. I rejected this paradigm as being too generalistic and ignoring the fact that inaction may have future consequences in itself, and also as being unethical by ignoring the present needs of the child as a 'being' in her own right rather than as solely a future 'becoming'.<sup>82</sup> Whilst I maintain this stance in general, in *this* context the positive action of the administration of hormone blockers in childhood actually allows for a wider range of possible identities in adulthood – so action would facilitate the right to an open future.

A key legal and ethical question that falls under Guideline One is whether a child such as Jackie, can be competent to consent to procedures that might not confer any medical benefit to their physical body, or whether it could ever be deemed to be in their best interests to do so. The first issue here is the process of identifying and diagnosing Gender Dysphoria. As discussed under Guideline 3 below, dysphoria may result from social constructions around gender and as a BBC Advice site notes; 'people who experience GD are not mentally ill, but they often suffer great stress because they are hiding their identity'.<sup>83</sup>

The second question concerns consent to treatment if that is the chosen route. There are echoes here with the debate around child organ donors, as discussed in Chapter 5, and whether it is ethically permissible to mutilate a healthy body for a purpose other than to improve the physical health of the child patient.<sup>84</sup> There are those, such as

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<sup>81</sup> Joel Feinberg, 'The Child's Right to an Open Future' in Aiken W and laFollette H (eds) *Whose Child?* (Littlefield, Adams & Co 1980).

<sup>82</sup> See Alison Diduck, *Law's Families* (LexisNexis Butterworths 2003) 81.

<sup>83</sup> BBC Radio, BBC Advice, 'Gender Dysphoria and Transgender'.

<sup>84</sup> Chapter 5.

Carlos Flores, who that contend that medical interventions intended to address Gender Dysphoria, cannot properly be categorised as medical treatment at all. He claims that whilst ‘medicine is the enterprise of restoring bodily faculties to their proper function’, these procedures involve ‘the intentional damaging and mutilating of otherwise perfectly functioning bodily faculties by twisting them to an end toward which they are not ordered’.<sup>85</sup> If true, this would render such procedures within the realm of cosmetic treatments and have implications for the ability of any person under 18 to be able to consent to them. Even for 16 and 17 year olds the FLRA 1969 only applies to ‘surgical, medical or dental *treatment*’,<sup>86</sup> and similar doubts as to the definition of treatment were raised by Lord Donaldson in relation to organ donation.<sup>87</sup>

However, under the Ethics of Care engrossment in the child’s experience would require real listening and an appreciation of the child as an expert in terms of their perception of their suffering and the means necessary to alleviate it. In Jackie’s case there was a certainty from a young age, as she explains; ‘I knew from the start I was a girl, it was just actually having the vocabulary to make people understand’.<sup>88</sup> In these circumstances, physical interventions such as the administration of hormones and even gender reassignment surgery *could* properly be deemed to be treatment for mental distress, akin to other therapies that use physical means to address mental conditions, such as ECT. However, the application of care might also reveal the need for caution as the child may be uncertain as to the nature of their feelings, and given the high rate of desistance in early childhood, there may be other solutions such as social transitioning which may be more appropriate. This is certainly in line with the broader approach of the Tavistock Clinic, whose aim is to support the development of

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<sup>85</sup> Flores (n35).

<sup>86</sup> S 8(1) - emphasis added.

<sup>87</sup> *Re W (A minor) (Medical treatment; court’s jurisdiction)* [1993] Fam. 64, [1992] 4 All ER 627.

<sup>88</sup> Murfitt (n1).

gender identity, by exploring in it the context of the development process. The aims of the service are to understand the nature of the obstacles or adverse factors in the development of gender identity, and to try minimise their negative influence.

Of course, the nature and implications of each kind of treatment differ. As Norman Spack notes:

When young people halt their puberty and take cross-sex hormones for a few years, they are likely to become infertile. You have to explain to parents that if they go ahead, they may not be able to have children. When talking to a 12 year old, that's a heavy-duty conversation.<sup>89</sup>

As such it may be that a child could be *Gillick* competent at the age of 13 to consent to the administration of puberty blockers but not to cross-sex hormones, given the more serious and long-term consequences of the latter treatment. Much of this hinges around the fact that puberty blockers are considered to be a wholly reversible procedure, but cross-sex hormones are deemed to be only semi-reversible. Indeed, since 1992 Australia has taken the approach that the administration of cross-sex hormones to minors has such serious consequences, in particular loss of fertility, that it falls within a 'special category of medical procedure' that have special rules that apply to them.<sup>90</sup> As a consequence, parents are not permitted to authorise it and nor can the healthcare professionals assess the child themselves for competence. Rather the issue must go before the Family Court for consideration - Australia is the only

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<sup>89</sup> Murfitt (n1).

<sup>90</sup> Adam Zwi, 'Transgender Children, the Law and a Boy Born in the Skin of a Girl' *The Guardian* (19 June 2016).

jurisdiction in the world that offers this treatment yet requires court authorisation for it.<sup>91</sup>

In contrast the UK takes a much more individualised approach, which is in line with consideration of the particular child as advocated by the Ethics of Care framework. Whilst there has been no case law directly on the issue of children's ability to consent to treatment for Gender Dysphoria, there has been one case which does involve the privacy of information relating to a child undergoing treatment for GD at the Tavistock clinic – *PD v SD, JD and X County Council*.<sup>92</sup> In *PD Keehan J* held that a 16-year old trans boy was able, by virtue of the provisions of the FLRA, to consent to receiving cross-sex hormones, without his parents consent.<sup>93</sup> This confirms that the modern view of the court is that medical care for Gender Dysphoria does indeed fall within the definition of treatment. Further, in line with care thinking, it would suggest that should a *Gillick* competent child seek treatment and the parents disagree or their relationship has broken down, that the views of the child should be determinative.

#### 4.2 - Embodied Experience

Another crucial factor in determining whether treatment for GD is ethically acceptable is attentiveness to the child's embodied experience. As explained in Chapter 2, the notion of embodiment is a key aspect of Guideline One. Because of the nature of GD, much of the dysphoria is centred on the physical body. This presents a dichotomy, as to the outside observer the body is functioning and healthy and it is the mind that is the site of the distress. But for trans activists, teaching the child that they

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<sup>91</sup> Zwi (n90).

<sup>92</sup> *PD* (n56).

<sup>93</sup> *ibid* para 20.

must be a boy or girl because their external genitalia says so is harmful and ‘further emphasizes their hatred of their body’ and ‘reinforces their feelings of discomfort’ to the point that it often leads to ‘eating disorders, self mutilation and suicide’.<sup>94</sup> Here the application of Motivational Displacement under the Ethics of Care would enable us to appreciate that intervention is not only compassionate, but for some children it is life - saving.

For those who feel that physical treatment for transgender feelings is unethical, such as Carlos Flores, the anatomical appearance reigns supreme. He argues that ‘no amount of surgical mutilation of body parts, effeminate behaviours, or artificial female appearances can make a man a woman’.<sup>95</sup> He claims that transgenderism is a mental disorder characterised by a false belief about one’s identity, akin to conditions such as anorexia nervosa. He therefore advocates that therapy is the appropriate way for a transgendered person to ‘relieve himself of his disordered transgender identity insofar as this would amount to a restoring of the transgendered individual’s mental faculties to their properly functioning state’.<sup>96</sup> However, this approach is not a mainstream view, as evidenced by the statement issued by The World Professional Association for Transgender Health that treatment aimed at trying to change a person's gender identity and expression to become more congruent with sex assigned at birth ‘is no longer considered ethical.’<sup>97</sup> Nor, would such thinking be in accordance with the Ethics of Care, for although those holding such views would claim that they care for the welfare of those suffering with Gender Dysphoria, they have missed the

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<sup>94</sup> TransKids Purple Foundation, Frequently Asked Questions < [www.transkidspurplerainbow.org](http://www.transkidspurplerainbow.org)>, Last accessed 24 June 2016.

<sup>95</sup> Flores (n35).

<sup>96</sup> *ibid*

<sup>97</sup> WPATH (n58).

essential step of engrossment in the situation of the child and instead impose their external biases upon the child.

For Jackie, her embodied reality was that ‘my body didn’t match because, as far as I am concerned, I had a birth defect’.<sup>98</sup> This point of view is that for Jackie her body was defective, something to be hidden and ultimately corrected, and as her mother Susie observed: ‘Having the anatomy of a boy was a constant reminder that she still wasn’t who she wanted to be’.<sup>99</sup> As noted by TransKids Purple Rainbow Foundation, this mental disconnect with the yet ever present reminder of the body is problematic for many transgender children; ‘At no point, regardless of how happy the child looks, are they truly comfortable in their body or with their expected social roles. Their only recourse is to dress as they identify and hope that no one remembers what is really under their clothes’.<sup>100</sup>

#### 4.3 - Unknown Effects of giving Hormone Blockers – Vulnerability and Trust

Although the effects of hormone blockers are reversible - with the aim of merely putting puberty “on hold”, concerns have been expressed over the long-term effects of these hormones on brain development, bone growth and fertility.<sup>101</sup> Additionally, there may be reservations over the long term psychological outcomes following hormone treatment, with Hewitt et al claiming that international studies suggest that behavioural problems and depression improve but anxiety, anger and Gender Dysphoria remained unchanged.<sup>102</sup> Here we see the vulnerable child, which is an essential part of the Ethics of Care framework, as explained in Chapter 2. Transgender

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<sup>98</sup> Murfitt (n1).

<sup>99</sup> *ibid*

<sup>100</sup> TransKids Purple Rainbow Foundation, Frequently Asked Questions <[www.transkidspurplerainbow.org](http://www.transkidspurplerainbow.org)> <Last accessed 24 June 2016>

<sup>101</sup> Laura Donnelly, ‘Rise in Child Transgender Referrals’ *The Telegraph* (7 April 2015).

<sup>102</sup> Jacqueline K Hewitt et al, ‘Hormone Treatment of Gender Identity Disorder in a Cohort of Children and Adolescents’ (2012) 196(9) *Med J Aust* 578. 580.



children are vulnerable in the sense that they are potentially exposing their bodies to unknown physical harms, yet they are also vulnerable on a deeper level by revealing their inner identity with the risk of public scorn or physical harm. Murfitt is correct in observing that ‘there is a real conundrum here between a desire to help children who are distressed psychologically and the potential physical pitfalls of hormone treatment’.<sup>103</sup>

This vulnerability may be mitigated somewhat by the application of trust, which as Baier contends is the middle ground between love and reason.<sup>104</sup> Here the value of mutual trust may be applicable when discerning a child’s best interests – trust that the treatment offered is the ‘best’ the healthcare profession have to offer in the circumstances and trust that the child receiving it will be benefited. This trust may need to be tempered with caution when the reality is that ‘you are asking someone aged as young as 11 to make big decisions about their adult life and identity’.<sup>105</sup>

The Australian case of *Re Alex*,<sup>106</sup> demonstrates this balancing of vulnerability and trust. It involved an application before the Family Court to determine whether the guardian of 10-year old Alex could provide consent to puberty blockers, and later cross-sex hormones, to address Alex’s GD. The court held that although Alex may have had a general understanding of the nature and purpose of the treatment he was not sufficiently mature to understand the full implications of the treatment and

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<sup>103</sup> Murfitt (n1).

<sup>104</sup> Annette Baier, ‘What do Women want in a Moral Theory?’ in Roger Crisp and Michael Slote (eds) *Virtue Ethics* (OUP 1997) 263

<sup>105</sup> Polly Carmichael: Tavistock Clinic News (25 May 2016)

<sup>106</sup> *Re Alex* (2004) Fam CA 297.

therefore was not competent to decide for himself. However the court did hold that it was in Alex's best interests to receive the treatment.

## **Section 5 - Applying Guideline Two: Consideration of the Child's**

### **Past and Future Caring Relationships.**

#### **5.1 - Impact of Family Relationships**

The application of the Ethics of Care framework under Guideline Two would provide greater subtlety than might be seen in the current approach by providing a clear focus on the impact of past and future care provided by those with whom the child has a relationship. The nature of these relationships may ultimately affect the viability of any treatment. Strong supportive relationships would be a positive indicator that treatment should proceed, particularly in light of evidence to show that this can be the key factor to treatment success.<sup>107</sup> For Jackie, 'astonishingly supportive parents'<sup>108</sup> were crucial in enabling her to make the choices that she did in relation to how she presented herself in the social world. As Susie explains, 'I'm really proud of her. She's been through an awful lot but she has chosen to put herself out there and at risk. There is a lot of prejudice out there but she is trying to make people understand this isn't a choice'.<sup>109</sup>

The dilemma of parents faced with a child suffering with gender dysphoria, can be tackled using Ruddick's maternal thinking, which begins with the goal of preservation and protection.<sup>110</sup> This would surely manifest itself in the desire to do what is required

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<sup>107</sup> NHS England, *Gender Identity Development Service for Children and Adolescents* (September 2016).

<sup>108</sup> Murfitt (n1).

<sup>109</sup> Julian Gaughan, 'Teenager who became Youngest Person to have Sex Change clinches Semi-Final Spot in Miss England Contest' Mail Online (20 May 2013).

<sup>110</sup> Sara Ruddick, *Maternal Thinking: Towards a Politics of Peace* (Beacon Press, Boston 1989) 70

to keep their child safe, even if that was safe from themselves. The characteristic attitudes to accompany this goal would be optimism, a hope that they were choosing the 'right' in most likely a situation which is alien to them, but combined with humility, that there is much that the parent could learn from the child.<sup>111</sup>For Jackie, her mother's lack of doubt about her daughter starting on hormone treatments at the age of 12,<sup>112</sup> would have enabled Jackie to move forward with confidence in undergoing treatment.

This is not to underplay the difficulties that many parents face. There may be struggles in adjusting to their child's GD. Often families are unable to comprehend their child's feelings or accept their child's new identity. They may experience grief as they perceive a loss of the child they gave birth to and the replacement with a different child. Trans-girl Nikki's mother expressed such sentiments when Nikki changed her birth certificate: 'I have a lot of memories of her as my baby boy (...) It was a grieving process for me. I was sad (...) And sometimes I'm still sad'.<sup>113</sup> This inability to understand was the cause of the family breakdown in the case of *PD*<sup>114</sup>, where the 16 year-old child chose to disengage with his parents because they failed to understand his desire to become a boy and they persisted in using his female name. As discussed in 4.1 above when a child is Gillick competent it appears that their views should be determinative.

However, when the child is more fluid in their gender choices and happy to experiment back and forth, surprisingly this can create greater stress within the family

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<sup>111</sup> Sara Ruddick, 'Maternal Thinking' (1980) 6(2) *Feminist Studies* 342, 352.

<sup>112</sup> Murfitt (n1).

<sup>113</sup> Elizabeth Day, 'Transgender Kids: 'Everyone was calling me Sebastian, but I knew I was a Girl' *The Guardian* (5 April 2015).

<sup>114</sup> *PD* (n56) para 33.

than for those whose assertion that they are in the “wrong body” is firm and persistent. As Michael Hogan noted when reviewing the Louis Theroux documentary, ‘such grey areas often resulted in family rifts: grandparents disapproved, fathers were in denial, mothers feared for their child’s future’.<sup>115</sup> Additionally, it may be heart-wrenching for parents to deal with their child’s distress, despite the support they are receiving from home, as the mother of trans-boy Martin recounts: ‘Our family unit is suffering. When I say goodbye to him everyday (...) I sit hoping he comes home from school. Everyday I tread water and counsel his depression, hoping he can hang on’.<sup>116</sup>

For children that are not *Gillick* competent, ultimately parental objection might act as a veto on treatment. This is both a pragmatic recognition that parental hostility is likely to undermine treatment success, and an acknowledgement that caring relationships are multi-faceted and that a holistic best interests assessment would give great weight to the child’s relational context. Of course this leaves the child in the difficult position of not being able to immediately receive the treatment that they desire, which for some children could have dire consequences. For Jackie, the ability to be able to access this treatment was literally life saving, as she explains; ‘It basically paused puberty and it saved my life (...) I would have killed myself. I wouldn’t have been able to cope’.<sup>117</sup> Here the Ethics of Care does not propose to offer any easy answers and in such a case, the matter may have to go before the court where best interests would be determined by the application of the factors of the welfare checklist or performance of a balancing exercise. The court may hold that treatment is in a child’s best interests such as in *Re Alex* discussed above, although in

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<sup>115</sup> Michael Hogan, ‘Louis Theroux: Transgender Kids, Review: “Excellent Storytelling”’ *Telegraph* (5 April 2015).

<sup>116</sup> Zwi (n90).

<sup>117</sup> Murfitt (n1).

this case there did not appear to be any parties objecting to the treatment. Using the Ethics of Care may indicate that where there is a genuine risk to the life of the child that this must outweigh any detrimental effect to the child's relationships, in ordering treatment to commence. However, in cases that fall short of this kind of threat, relational matters might be given great weight in any assessment of the child's welfare.

Certainly the role of parents has featured heavily in the debate about the nature of transgenderism and overbearing parental encouragement to adopt an alternative gender identity in the absence of any clear desire to do so by the child, would also be a contraindication for treatment. In an article for *The Telegraph*, Laura Donnelly discusses the case of 8 year-old "Jessica", a m-f transgender child, who from an early age felt that she had been born into the wrong body but whose parents had been accused by a relative of "conditioning" their child and 'forcing their boy to live as a girl'.<sup>118</sup>

Although, as Milrod claims for transgender children coercion is unlikely to be present as a factor compelling the child to seek treatment,<sup>119</sup> beginning with an Ethics of Care approach centred on the relationship itself will help to discern whether there is abuse or undue influence present. Here caring justice could be applied in order to scrutinise the nature of the relationship, which would mean starting from a presumption of care and a positive relationality but then overlaying the assessment with principles of justice which would weigh up the liberty of the child to choose for themselves or the

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<sup>118</sup> Laura Donnelly, 'Rise in Child Transgender Referrals' *The Telegraph* (7 April 2015).

<sup>119</sup> C Milrod, "How Young is too Young: Ethical Concerns in the Genital Surgery of the Transgender MTF Adolescent (2014) 11 *Journal of Sexual Medicine* 338.

presence of any subversive motives of the parent. Such a situation was evident in the case of *Re J*,<sup>120</sup> where Hayden J held that 7 year-old J's mother 'was determined that J should live life entirely as a girl' and was encouraging him to do so 'by stealth' without any formal diagnosis of GD or any sustained wish on the part of the child to do so.<sup>121</sup> The court applied what I would contend was a care approach in order to uncover the nature and quality of the relationship between J and his mother, something that the authorities had apparently been unable to do. Drawing upon expert evidence it was apparent that the relationship that J had with his mother was 'emeshed' to such an extent that she was unable to distinguish her feelings from his. This would be contrary to the embodiment suggested by the Ethics of Care, which although favours proximity and partiality is always motivated by an understanding of the views of the other free, from personal bias. As a result of this dysfunction of relationship the court concluded that the mother had 'caused significant emotional harm to J', that she had 'overborne his will and deprived him of his fundamental right to exercise his autonomy in a most basic way'.<sup>122</sup>

## 5.2 - Social Transitioning

Social transitioning, where the child adopts the clothing or hairstyle of their chosen gender or uses a name and/or pronouns that reflect that gender, is also not without ethical challenge. This social transition often happens at the bottom end of the mid-childhood range at around the age of 7 or 8, and at its worst can be a mechanism of control as was seen in the case of *Re J*. Here the child had completely socially

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<sup>120</sup> *Re J* (n57)

<sup>121</sup> *ibid* para 39.

<sup>122</sup> *ibid* para 73.

transitioned from the age of 5,<sup>123</sup> and although in this case the mother purported to have her son conceal his gender dysphoria to protect him from bullying,<sup>124</sup> the court found that social transitioning was a way for her to manipulate her sons's gender identity and was 'fraught with the potential for real harm if his true gender identity was inadvertently discovered'.<sup>125</sup> However, for most parents, social transitioning allows for the opportunity of exploration and adaption without any firm commitment from either parent or child. The Tavistock approach places relationships at the heart of their work and recognises that they are as important as other factors in contributing to the patient's difficulties. For Susie, Jackie's social transition at the age of 8 was a source of comfort, as she remembers; 'Jackie was so much better after that, more content than I'd seen her in years'.<sup>126</sup> However for many parents the dilemma remains. As Michael Hogan commenting on the Louis Theroux documentary observes that early diagnosis of young children with GD then leaves their parents 'with a stark choice: do they start "transitioning" a child still developing its own identity, or wait and risk making the change once their body has gone through puberty?'<sup>127</sup>

### 5.3 - Age at which Cross-Sex Hormones or Gender Reassignment Surgery should be Permissible

The final issue under Guideline Two is the issue of the administration of cross-sex hormones, or undertaking of gender reassignment surgery.<sup>128</sup> Because of the serious, and in the case of surgery, irreversible nature of the procedure professional guidelines recommend that the child be at least 16 years-old to receive cross-sex hormones and

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<sup>123</sup> *Re J* (n57) para 41

<sup>124</sup> *ibid* para 59.

<sup>125</sup> *ibid* para 39.

<sup>126</sup> Murfitt (n1).

<sup>127</sup> Hogan (n115)

<sup>128</sup> Johanna Olson et al, 'Baseline Physiologic and Psychosocial Characteristics of Transgender Youth Seeking Care for Gender Dysphoria (2015)57 Journal of Adolescent Health 374, 379.

18 for surgery.<sup>129</sup> On one hand it may be fair to attribute caution to the ‘problematic grey area in differentiating so early between sexuality and gender identity’.<sup>130</sup> As the father of 14-year old trans girl Nikki reveals:

I did not have an idea what to do. It was: how do we navigate here? There was an option that we should proceed with caution and not let this happen, but (...) it becomes evident its not a very good direction to take. It leads to all the wrong things, all the things you don’t want your child to go through – lack of self-esteem, not being their natural self’.<sup>131</sup>

An application of the Ethics of Care would reject stark age thresholds as not particularist enough, and so would seek to move beyond this to allow for more flexibility dependent upon the child’s circumstances, understanding, physical and emotional maturity and relational support. For Jackie early administration of cross-sex hormones at the age of 13 and surgery at the age of 16 was life-affirming as she recalls; ‘It’s hard to find words strong enough to describe how I felt when I woke up. It was like “Wow, my life really does start now. I cried tears of joy”’.<sup>132</sup> A more particularist approach is endorsed by Transgender Charity Mermaids who contend that:

for parents this is very emotive because you can see your child suffering but do nothing about it. It is great that Tavistock is prescribing but the age limits of 12 and 16 are too high. We want them to let children start treatment based on how they are developing, not age’.

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<sup>129</sup> WPATH (n58)

<sup>130</sup> Murfitt (n1).

<sup>131</sup> Elizabeth Day, ‘Transgender Kids: ‘Everyone was calling me Sebastian, but I knew I was a Girl’ *The Guardian* (5 April 2015).

<sup>132</sup> Murfitt (n1).



There has been a slight but promising move towards greater flexibility in the latest NHS Guidelines on treatment with Cross-Sex Hormones that recommends that treatment may start ‘at *around* 16 years’.<sup>133</sup>

## **Section 6 - Applying Guideline Three: Evaluation of the Social**

### **Context of Care.**

#### **6.1 -Social Expectations, Stigma and Labelling**

Many trans activists assert that it is social expectations around gender roles and the ensuing stigma and labeling for non-compliance that are the real source of Gender Dysphoria. They object to society's determination to frame everything in terms of the gender binary, as graphically illustrated by Io Wright who argues that ‘male and female are the two pillars upon which our society is built. Gender dictates everything from what kind of relationship you get into to where you take a piss. And if you upend that, it’s very threatening for people. It challenges the system by which they live’.<sup>134</sup> There are even those who would go as far as to reject imposing the gender binary upon infants at all, instead raising them in a gender neutral environment.

Part of the mission statement of Transkids Purple Rainbow Foundation is that ‘Gender Dysphoria is something a child can’t control and it is society that needs to change, not them. Families need to support their children and be encouraged to allow them to grow up free of gender roles’.<sup>135</sup> On one hand, there are many that would seek

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<sup>133</sup> NHS England, *Clinical Commissioning Policy: Prescribing Cross-Sex Hormones as part of the Gender Identity Development Service for Children and Adolescents* (August 2016) 15.

<sup>134</sup> Thu-Huong Ha, ‘How should we talk about Transgender Issues’ Ideas.Ted.com (31 March 2014).

<sup>135</sup> TransKids Purple Rainbow Foundation< [www.transkidspurplerrainbow.org/about-us/](http://www.transkidspurplerrainbow.org/about-us/)>, Last accessed 24 June 2016.

to maintain the importance of traditional gender roles and identities, often informed by cultural or religious viewpoints. For example, some conservative thinktanks argue that only natal biological sex is the ‘truth’ and that public policy and social norms should be constructed to ‘reflect the truth about the human person and sexuality, not obfuscate the truth about such matters and sow the seeds of sexual confusion in future generations for years to come’.<sup>136</sup> Yet on the other, as awareness of trans issues increases in the public perception, there is a rare danger that in a commendable desire to be accommodating and non-discriminatory, issues that are in need of scrutiny are overlooked. This was evident in *Re J*, where Hayden J upbraided social services and healthcare professionals for not intervening sooner in J’s case. He noted that the ‘profile and sensitivity of the matters’ had ‘blinded a number of professionals from applying their training, skills and it has to be said, common sense’ as they ‘did not wish to appear to be challenging an emerging orthodoxy in such a high profile case’.<sup>137</sup>

There is inevitably a tension for parents as they move out from the individual world of the child’s experiences and the comfort of caring relationships, into the social world. The physical appearance of transgender people may draw attention and consequently they may find it difficult to operate successfully within social situations, as Jackie notes; ‘A lot of transsexuals have distinctive features, because they haven’t been able to take the blockers early like I did. This makes them stand out, making it much harder to fit into society, especially when it comes to a job’.<sup>138</sup> Norman Spack

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<sup>136</sup> Flores (n35).

<sup>137</sup> *Re J* (n57) para 75.

<sup>138</sup> Murfitt (n1).

confirms that identity and “fitting in” are the values that are most important to them.<sup>139</sup>

The application of the Ethics of Care may demonstrate how to reconcile social expectations around gender roles and ‘good parenting’ with the desire to meet the needs of the child. Some trans advocacy groups urge transgender children to resist social pressure to conform by claiming that ‘teaching your child to “be what others expect” is contrary to developing a good sense of conscience and self-esteem’.<sup>140</sup> However Ruddick’s second and third goals of maternal thinking may offer a more subtle analysis. Under her second goal the one-caring would seek to maximize the developmental interests of the child. However acceptability in the social world, should not be bought at all costs and as Ruddick reminds us the challenge is to seek to reconcile the two goals in the quest for authenticity. This desire to be her authentic self was what drove Jackie to make the choices she did:

I have always been very sure and known what I wanted and who I am. I will say that if you are unsure because you are worried about how people will react and you feel people may think of you as selfish, then don’t. Is it not selfish of them to expect you to live in the wrong body knowing how much pain you are in and how much you are suffering? You are who you are and people should be able to accept you for that’.<sup>141</sup>

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<sup>139</sup> *ibid*

<sup>140</sup> TransKids Purple Rainbow Foundation, Frequently Asked Questions <[www.transkidspurplerainbow.org](http://www.transkidspurplerainbow.org)>, Last accessed 24 June 2016.

<sup>141</sup> Joseph Patrick McCormick, ‘Interview: Jackie Green, the First Trans Miss England?’ Pink News (27 January 2012) <[www.pinknews.co.uk/2012/01/27/interview-jackie-green-the-first-trans-miss-england/](http://www.pinknews.co.uk/2012/01/27/interview-jackie-green-the-first-trans-miss-england/)>

## 6.2 - Education, Public Policy and a Clash of Minority “Rights”

The first experience that a transgender child may have in the social world may be at school. Natacha Kennedy claims that transgender children are one of the most marginalized and excluded groups<sup>142</sup>; indeed most children with GD suffer from high levels of social anxiety and attention deficit disorder'.<sup>143</sup> The social pressures to conform may have an impact on their education, which can have longer-term effects on the quality of their education and ultimately how productive they are in society as adults. This is particularly evident as children reach mid-childhood and in many ways become less accepting of difference. As Jackie recalls 'secondary school was horrible. I was being spat on, being beaten up and called so many different names. The parents were the worst'.<sup>144</sup>

Whilst caring public policy would support social transition of children at school, the transgender bathroom controversy discussed in the introduction is a good example of the result of an absence of care. In order to resolve this issue through the Ethics of Care, an application of caring justice would be instructive. Using rights language merely serves to pit one interest against another, and raises suspicion. Whilst the application of the Ethics of Care would begin from a presumption of harmony and by examining the relationship between social actors seeks to uncover, if and where any threat truly lay. To begin with an orientation of care would indicate that the primary individual and relational needs of the trans child appear to be identity and fitting in as indicted by Norman Spack, above. This would suggest that the preferred option for most trans children would be to use the bathroom of their chosen gender. Applying an

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<sup>142</sup> Natacha Kennedy, 'Transgender Children: More than a Theoretical Challenge' (2012, Goldsmiths College, University of London), 1.

<sup>143</sup> TransKids Purple Rainbow Foundation, Frequently Asked Questions <[www.transkidspurplerainbow.org](http://www.transkidspurplerainbow.org)>, Last accessed 24 June 2016.

<sup>144</sup> Murfitt (n1).

overlay of justice would help us to identify the potential concerns around safety and discrimination. Some have argued that by allowing transgender people to use the bathroom that matches their chosen gender, they are undermining the rights of another minority group – namely women, to be free from sexual harassment. As Mary Wakefield explains the fear is that ‘if trans people are allowed in the loo of their choice, the fear is that schoolboys and perverts will identify as female just to gain access and grope girls’.<sup>145</sup> Wakefield goes on to argue that liberal language is being co-opted by those with a ‘trans agenda, claiming that ‘it’s interesting that it’s the very same liberal voices who have in recent years been so agitated about girls rights, now say any worried women should pipe down (...) This is because 21<sup>st</sup> century rights are not equal but hierarchical; the most disadvantaged first’.<sup>146</sup>

But the application of justice by its very nature needs to be measured and fair. Whilst it is true that public policy does need to cater for the needs of the many, and that potential solutions are that all bathrooms could become unisex or that trans children could use special gender neutral bathrooms, neither option satisfactorily addresses the needs of trans children *or* the concerns of objectors. The first policy would be impractical to execute given the segregated constructions of most bathrooms in public buildings (with the presence of urinals in men’s bathrooms for instance) and if there were genuine fears around abuse and harassment of women, the risk is much greater if men can share women’s bathrooms as opposed to women sharing with a few trans women. The second policy would lead to exclusion or othering of transgender children, which merely acts to reinforce the stigma felt by those children whilst

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<sup>145</sup> Wakefield (n 4).

<sup>146</sup> *ibid*

failing to acknowledge that the bathroom of choice policy did nothing to endanger the interests of the majority in the first place.

### 6.3 - Resource Allocation

The final issue in the evaluation of the social context of care is the question of resource allocation, when one considers the cost of treatment for transgender children that would be borne by the NHS. In Jackie's case, her parents privately funded her treatment in the USA and Thailand, which totalled £28,000, £15,000 for the hormone treatments and £13,000 for the surgery, by re-mortgaging their home.<sup>147</sup> As noted above, some may argue that the NHS should not fund what could be considered to be cosmetic procedures and it is clear that the research evidence around the long-term impacts of some of the treatments is still developing.<sup>148</sup> However, such approaches can be properly classed as legitimate treatments, and they appear to be largely successful in ameliorating the effects of GD.<sup>149</sup> Whilst resource allocation considerations might properly be a limiting factor, at least in the public sphere, on the scope of care, the relatively modest costs of hormone treatments are surely offset by the savings made in by not having to provide years of therapy, or medical care after self-harm or suicide attempts.<sup>150</sup> As Reed rightly contends, 'Physical intervention in early puberty would relieve stress and prevent the development of unwanted

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<sup>147</sup> Murfitt (n1).

<sup>148</sup> NHS England, *Gender Identity Development Service for Children and Adolescents* (September 2016) 7.

<sup>149</sup> See for example, NHS England, *Clinical Commissioning Policy: Prescribing of Cross-Sex Hormones as part of the Gender Identity Development Service for Children and Adolescents* (August 2016).

<sup>150</sup> Johanna Olson et al, 'Baseline Physiologic and Psychosocial Characteristics of Transgender Youth Seeking Care for Gender Dysphoria (2015) 57 *Journal of Adolescent Health* 374, 379.

secondary sex characteristics, which later require costly and painful correction.... It seems cost effective to identify transsexual people early and offer them treatment'.<sup>151</sup>

### **Concluding Thoughts**

This case study has demonstrated the difficult tensions involved in seeking to treat children for gender dysphoria. It has illustrated how for transgender children mid-childhood, with the commencement of puberty, is a key time in the development of their understanding of their identity. A response based on the Ethics of Care can help to facilitate good decision-making whilst an absence of care can be the cause of much distress, ultimately leading in some cases to self-harm and suicide. The analysis of Jackie's case has revealed the importance of real attentiveness and engrossment in the situation of the individual child and the key role that embodied experience plays in decision-making about treatment. An examination through the Ethics of Care of the quality and nature of the caring relationships in Jackie's life showed the importance of relationality in bolstering her confidence, whilst acknowledging the difficulties many families face when confronted with the reality of a transgender child. Finally, the evaluation of the social context of care, shed light on the impact of relationships in the wider world in terms of the child's construction of their identity and finding their place in the social world. In sum, Jacqueline Hewitt right observes that transgender children should be recipients of care as the 'experience of growing up in a body which feels alien is difficult and confusing. Profound GD represents a mental health crisis in childhood, with implications for problematic psychosocial and relationship development throughout life (...) children and adolescents with GD suffer with a great burden of morbidity and are deserving of optimal medical care'.<sup>152</sup>

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<sup>151</sup> Reed (n17) 18.

<sup>152</sup> Hewitt (n51) 581.

## **CONCLUDING THOUGHTS**

### **Introduction**

My thesis opened with reference to *My Sister's Keeper* and the assertion by DeSalvo J in the story, that when it comes to making difficult decisions about our health and bodies 'morals are more important than ethics, and love is more important than law.'<sup>1</sup> Whilst recognising the crucial role that intuitive morality and emotional connection play, my search was for an ethical approach that could successfully bring these together with a decision-making process that was able to operate within the certainty of the law. My focus was to explore this question within the context of healthcare decision-making for children in mid-childhood. In the introduction I asserted that the current legal and to a lesser extent, medical, mechanisms are inadequate to fully reflect children's interests in, and capabilities to, participate in matters relating to their own health.<sup>2</sup> I therefore sought to find an alternative ethical approach to children's decision-making based upon the Ethics of Care. My key thesis question was 'Is the 'Ethics of Care' an appropriate and workable normative ethical basis for healthcare decision-making relating to children in mid-childhood and if so, how could it be used by policy makers and the courts?'

I have demonstrated throughout this thesis that the traditional mechanisms for decision-making do indeed fall short of enabling children to be fully involved, whether that be through establishing their competence or voicing their opinions. Focal

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<sup>1</sup> Jodi Picoult, *My Sister's Keeper* (Hodder & Soughton 2004) 393.

<sup>2</sup> Introduction 6-7.



themes throughout have been the tensions between the individualistic, abstract notion of the child patient within both the law and medical ethics and the concrete practical reality of the child, which is one of interconnection and relationality. These tensions were played out in the story of *My Sister's Keeper*, where at first it appeared that DeSalvo J was wrong about love being more important than law, as Anna rejected her relational responsibilities towards her sister in favour of her individualistic desires. Yet the adoption of relational thinking that is at the heart of the framework that I have presented in this thesis does not necessarily require relationships to be cast in a “rosy glow”. Developed from Jo Bridgeman’s three normative guidelines of care, this framework seeks to uncover the needs and voice of the child interconnected in the reality of the web of relationships in which she lives – good or bad. Indeed, it was apparent that relationality still resided at the heart of Anna’s decision, albeit informed by an apparently negative view of her relationship with Kate. However, the twist in the story revealed towards the end makes Anna’s story an even more pertinent example of the operation of the Ethics of Care. We discover that Anna’s refusal to donate her kidney to Kate was actually an expression of her close loving relationship with her sister, as Kate had confided in Anna that she did not wish to be a recipient as she had had enough suffering and wished to die. Sometimes placing relationships at the centre of our decision-making shows us that the most caring action is inaction.

As discussed throughout my thesis I contend that the Ethics of Care framework has been successful in plugging the normative gap left by the traditional operation of law and medical ethics. My overall thesis aim was split into four sub-questions and it is to those that I now turn:

## **1. Is the Ethics of Care a fitting Ethical Approach to underpin Healthcare Decision-Making?**

In Chapter 1 surveyed the genesis, developments and criticisms of the Ethics of Care and concluded that it was indeed a fitting ethical approach to underpin healthcare decision-making. In particular, my model drew heavily on the work of the early proponents of care. The work of Gilligan was perceptive in arguing that the impartiality portrayed by abstract principles was not a realistic portrayal of the relatedness that actually exists between persons. Additionally, her work was also foundational in highlighting how the experience of women had been ignored in moral philosophy. By choosing the maternal model, Ruddick's work acted to give credence to the experience of many women that were undertaking the daily work of care. It can be difficult to accept her claim that women's 'maternal thought', exists in a 'radically different way', to that experienced by men because of the way that women receive early maternal love with 'special attention to its implications for our bodies, our passions and our ambitions'.<sup>3</sup> However her work highlights the unique biological bond between mother and child and reflects the reality that most care labour is carried out by women. That being the case, it is empowering to women with 'maternal' experience, to have their ways of thinking recognized and validated as being just as valuable as the traditional masculine ways of thinking.

The writings of Nel Noddings were especially valuable for highlighting not only the thought processes that accompany care but the importance of the particular as it relates to daily concrete experience. As Rosemarie Tong notes, 'For Noddings, caring is not about feeling favourably disposed toward human beings in general; rather, it is

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<sup>3</sup> Sara Ruddick, *Maternal Thinking: Towards a Politics of Peace* (Boston, Beacon Press 1989) 346

about concrete interactions between particular persons'.<sup>4</sup> Noddings skillfully validates the benefits of partiality as felt for those closest to us in a way that is able to overcome the objections to traditional impartial theories. Indeed a partialist approach avoids the conflict between what moral principles require of us and what we feel naturally, for it is these natural feelings that become part of the morality of the partial decision, thus circumventing impartiality's undermining of 'an individual's pursuit of her own ends, with her commitment to deeply cherished beliefs and commitment to particular people, groups and traditions'.<sup>5</sup> Yet partiality appears to be tempered by mechanisms of justice, which summon 'ethical care' in scenarios where we move from the ease of 'natural caring' to those where we are required to relate morally to others to whom we are naturally disinclined, or we see as 'undeserving' of such care. Such a mechanism can be an especially useful tool to demonstrate how care could operate in areas that have traditionally been deemed as solely within realms of justice, such as the law.

Of course care is not without its difficulties and I acknowledged in Chapter 1 some of the problems with the vagueness of definition, its nature and moral source. Notwithstanding this, I am convinced that care can be a fitting normative theory, working alongside theories of justice. if needs be, in order to underpin legal reasoning. This discussion was drawn together by my advocating an approach to care based upon Jo Bridgeman's concept of relational responsibility.

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<sup>4</sup> Rosemary Tong *Feminist Approaches to Bioethics: Theoretical Reflections and Practical Applications* (Westview Press 1997) 41.

<sup>5</sup> Helga Kuhse, *Caring: Nurses, Women and Ethics* (Blackwell, Oxford, 1997) 132.

## **2. What are the Important Factors in Children's Decision-Making in Healthcare Matters?**

The second sub-question was addressed in Chapter 2, where the conceptualization of the child in mid-childhood was considered. The important factors that were identified in this chapter were the predominance of developmental psychology and how that has both fostered and stifled children's participation, by encapsulating them in the modern paradigm posited by Diduck of 'Romantic Developmentalism'. The impact of sociological constructions of the child also came to the fore, with the key theme being enabled to view the child as a present 'being', which Dwyer argues is possessed of characteristics that are to be prized in terms of moral development. Within the law, tensions were identified between a protectionist desire based on fostering the child's welfare and the modern drive to protect and celebrate children's rights.

In order to navigate these multitudinous themes, and better address the key legal tests of *Gillick* competence and best interests, I present my Ethics of Care framework developed from the work of Jo Bridgeman. It consists of three guidelines which are flexible enough to capture to meet the particularism demanded by care yet imbued with factors which are pertinent to children in mid-childhood. The First Guideline is 'Attentiveness to the Individual Child in her Particular Circumstances', with the facets of this guideline being vulnerability, embodiment and participation. Guideline Two moves outward and is 'Consideration of the Child's Past and Future Caring Relationships', and encapsulates the facets of the relational self, and the child as holder of expertise. The Third Guideline is 'Evaluation of the Social Context of Care', considers the facet placing the child in her broader social, cultural and religious context.

### **3. How have the Courts addressed Mid-Childhood Healthcare**

#### **Decision-Making and is the Ethics of Care Compatible with**

#### **Principles such as Best Interests or *Gillick* Competence?**

The third sub-question was addressed in the systematic review found in Chapter 3. Here I critiqued the best interests test by way of examining 5 main criticisms but argued that retention of the test was the pragmatic choice. Instead, my contention was that both the best interests test and the *Gillick* competence test could be interpreted through the lens of the Ethics of Care. This thesis was tested out by identifying all mid-childhood healthcare cases from 1990-2016, and analyzing the judgments by applying my 3 guidelines of care. The small case study at the end of the chapter on the case of *F v F I* contend successfully illustrated how the Ethics of Care could produce a more subtle kind of judicial reasoning and more clearly identify the relevant aspects of the case.

### **4. How could the Courts or Healthcare Professionals use the Ethics of**

#### **Care to Aid in Mid-Childhood Healthcare Decision-Making?**

The final thesis sub-question was addressed within chapters 4-6: the case studies. Here the care framework was utilized in three novel areas of healthcare law and practice that gave rise to keen ethical dilemmas. In each the framework was able to highlight the importance of relationships and how ‘care thinking’ is central to children’s decision-making. Should these types of cases come before the courts, judges could be more explicit in their adoption of care reasoning, whether that be in being more open to considering that younger children could be *Gillick* competent or

being prepared to adopt a broader and more relational form of best interests. Within professional guidelines there is already evidence of care thinking, for instance in the 6 C's adopted by nursing. There is however the question of how to foster the Ethics of Care in a day to day sense in professional roles. Groenhout has noted that being a caring person does equip one well for certain roles, especially those that involve interpersonal interaction and the consideration of intimate relationships.<sup>6</sup> However, I am persuaded by Noddings' thesis that care can be a *learnt* behaviour through the development of 'ethical caring'. This can apply equally to judges, who although outsiders to the relationship in question, must nonetheless comprehend the complexities of it if they are to make sound and holistic judgments. Groenhout remarks that:

[o]ne is a better judge, for example, if one is capable of an empathic understanding of others, and one is a poorer judge if one finds others to be a complete mystery as far as motives, impulses, and purposes are concerned.<sup>7</sup>

## **5 Dealing with the 'Dark Side' of Care**

Of course care is not without its limitations and I make no claims for its universal applicability, although I am convinced that it is always an appropriate starting point. Implicit within the Ethics of Care is the difficulty in achieving moderation and balance in the caring relationship, where at its worst 'care' can act as a cover for neglect and abuse. On one hand there is the potential for paternalism/maternalism where those caring may take too much power in their caring relationships or come to

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<sup>6</sup> Ruth Groenhout, 'Care Theory and the Ideal of Neutrality in Public Moral Discourse' (1998) 23(2) *Journal of Medicine and Philosophy* 170, 175.

<sup>7</sup> *ibid* 175

‘accept their own account of what is necessary to meet the caring need as definitive’.<sup>8</sup> Here ‘engrossment’ may tip over into obsession with, or domination or abuse of the ‘cared-for’. On the other hand, we find the care-giver who is confronted by an unwilling or ungrateful recipient. Critics of the Ethics of Care such as Sarah Hoagland fault care for focusing too much on reciprocity and ‘successful’ caring relationships, whilst neglecting those examples where the recipient is unwelcome to care, takes it ‘as entitlement’ or even ‘skillfully takes advantage of the one-caring, so much so that the one-caring settles for any sign that her or his thoughts and actions are appreciated’.

Nancy Crigger examines Noddings’ recognition in her later work that unequal relationships can become unhealthy when ‘individuals subordinate their desires to another person who exploits them’,<sup>9</sup> a practice Noddings deems to be ‘pathological caring’.<sup>10</sup> A powerful way to tackle the force of these criticisms is to view care, not as a facilitator for dominance or abuse but to see it as a mechanism to shed light on the moral implications that reside in the asymmetry of caring relationships. Tove Pettersen argues that the very fact that relationships ‘extend in all directions’, with some engendering care whilst others give way to conflict and violence provides a fruitful source of study for care ethicists.<sup>11</sup> This is a positive benefit because as care accentuates and values features that other moral theories neglect, such as a wide scope of relational interactions, it can be alert to and address, dangers such as ‘structural violence, which can infect relationships between institutions and individuals’.

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<sup>8</sup> Joan Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (Routledge 1993) 14.

<sup>9</sup> Nancy Crigger, ‘The Trouble With Caring: A Review of Eight Arguments Against an Ethic of Care’, (1997) 13(4) *Journal of Professional Nursing* 217, 218.

<sup>10</sup> Nel Noddings, ‘In Defense of Caring’ (1992) 3(1) *The Journal of Clinical Ethics* 15.

<sup>11</sup> Tove Pettersen, ‘The Ethics of Care: Normative Structures and Empirical Implications’ (2011) 19(1) *Healthcare Analysis* 51.

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